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SOCIAL AND CULTURAL BARRIERS TO EDUCATION

Strategies to increase access to education for children living with HIV in Vietnam: A Minor Field Study

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Minor Field Study

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ABSTRACT

This thesis explores stigma in regards to access to education for children affected by HIV/AIDS in Vietnam and strategies to overcome stigmatization. This study is based on previous research which claims that HIV-related stigma causes isolation, bullying and social exclusion among affected groups. As a result, Goffman's theory of stigma was used together with Bourdieu's theory of capital and Foucault's concept of power. Nine in-depth interviews were conducted with practitioners in Hanoi. In spite of stigma, my findings suggest that social and cultural barriers are additional obstacles which severely limit access to education for vulnerable children. Such barriers entail poverty and inequalities in age, gender, class, ethnicity, orphan-status and geographical location. In conclusion, stigma-reducing interventions such as self-help groups, documentaries and participatory led awareness campaigns are efficient strategies to reduce stigma. Nevertheless, unequal access to education is caused by structural oppression which creates powerlessness. This must be challenged by promoting democratic participation and eliminating corruption since participation is power.

Keywords: Stigma, HIV/AIDS, education, power and capital, inequalities

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List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral therapy
CBO	Community-based organization
GDP	Gross Domestic Product
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
MDGs	Millennium Development Goals
MOET	Ministry of Education and Training
MOH	Ministry of Health
MOLISA	Ministry of Labor, Invalids and Social Affairs
NGO	Non-governmental organization
ODA	Official Development Assistance
PLWHA	People Living With HIV/AIDS
SEK	Swedish Krona
UNAIDS	United Nations Program on HIV/AIDS
UNDP	United Nations Development program
UNICEF	United Nations Children's Emergency Fund
VND	Vietnamese Dong

1. Introduction

A few years ago, I travel to Vietnam for the first time and became very fascinated by the Vietnamese history and culture. Since then I have traveled to Vietnam every year. In 2015, I had the opportunity of conducting an internship in Hanoi, the capital of Vietnam. After spending some time in the country, I came to realize that education is the number one priority in Vietnam. This reminded me of Sen (2001) who claims that education is the means and the ends to development. In fact, the right to education has been a central part in both my social work studies as well as my master program in development studies.

Then I started to search for a research topic and found an article by Boggiano et al. (2014) which describes that children affected by HIV/AIDS are excluded from schools in Vietnam because of stigmatization. There are strong HIV anti-discriminatory laws in Vietnam in order to ensure equal rights to education. Nevertheless, these laws are not implemented due to public stigma concerning HIV/AIDS. As a matter of fact, Vietnamese children with HIV have been excluded from schools because of parental protests (Boggiano et al., 2014:171).

These findings really bothered me. It felt so unfair. This issue is important because children without education are at risk of child labor, poverty and exploitation. Personally as a social worker, social exclusion and injustice are key interests of mine. I wanted to learn more about what is done to help these children have a better life. Therefore, I decided to write my thesis about access to education for children living with HIV and hopefully bring light to this issue.

First and foremost, I wanted to investigate how we can understand stigmatization of children living with HIV? How can we reach a deeper understanding of stigma? How can the concept of metaphors aid us to understand stigmatization? Secondly, I wanted to explore what policies and preventative measures are used by the government and NGOs to promote equal rights to education in Vietnam? What does their preventative work entail and how efficient is it? I also wanted to

know what other barriers hinder access to education for these children. Apart from stigma, what social, cultural and moral barriers are there for children to access education in Vietnam? Also, what barriers are hindering preventative work? Eventually, these thoughts were developed into a specific aim and research questions which are presented below.

1.1 Aim and research questions

The aim of this study is to gain a deeper understanding of the stigma and barriers which children with HIV face in regards to education in Vietnam and to analyze the strategies practitioners implement to promote equal rights to education and prevent stigmatization.

Main research question:

- How do practitioners work in order to prevent stigmatization and ensure equal rights to education for children living with HIV in Vietnam?

Sub-questions:

- According to the informants, what are the main challenges for children living with HIV and how does stigma influence the children's access to education?
- What kind of cultural and social meanings are tied to the social construction of HIV in Vietnam?
- What are the social and cultural barriers in preventative work and access to education for children living with HIV?
- Is the practitioners' work aimed at the children's adaptation and coping with stigma, or focused at developing knowledge and awareness/ understanding/ acceptance among the public and general population?

2. Background

In the following chapter I would like to provide some background knowledge about the research topic and the context of Vietnam. The issue of HIV and access to education will be presented as well as the Vietnamese political system.

2.1 The context of Vietnam

Vietnam[1] is a middle income country in South East Asia with a population of 90 million people. According to the World Bank (2016), Vietnam has made significant achievements in relation to achieving the Millennium Development Goals (MDGs). Thanks to globalization and a shift from planned economy to market-based economy; an estimated 30 million Vietnamese people have been lifted out of poverty the past three decades.

However, a market-driven economy makes the labor market highly exclusive. Education becomes a must in order to fully participate in a knowledge based society and be able to access and benefit from the possibilities offered by globalization. The country has made remarkable progress in education. Nowadays, above ninety percent of all children attend elementary school. More children in the rural and low income regions complete primary and secondary education (World Bank, 2016).

[1] Picture: Vietnam Travel Guide, 2015 www.vietnam-travel-guide.net

Nevertheless, Vietnam is facing new challenges mainly growing inequalities. Ethnic minorities and the poor face persistent lower education performance. Increasing gaps between the rich and poor create an urgent need for sustainable social interventions. Families in rural areas are plunging deeper into poverty. Most of Vietnam's poor live in remote rural areas. Elementary school is not free in Vietnam and there are costs associated with school such as; books, pens and uniforms. As a consequence the poorest children are not able to complete or attend school. The World Bank argues that Vietnam's education system is in need of more public funds and these funds must be used more effectively. This is an area for social workers to engage in policy making and implementation of policy (World Bank, 2016).

In 2013, approximately 250,000 people were living with HIV/AIDS in Vietnam (UNAIDS, 2014). HIV is mostly spread amongst drug users and within the sex industry in Vietnam. As a consequence, there is a lot of stigma and discrimination concerning this illness. People avoid getting tested because they risk social exclusion within the family, labor market and society (Nguyen et al., 2012:343).

2.2 Vietnam's political system

Some background information is needed about Vietnam's political system. The analysis contains specific information about the different governmental agencies. In order to clarify I have outlined the main agencies within the state's apparatus in Figure 1.1 below.

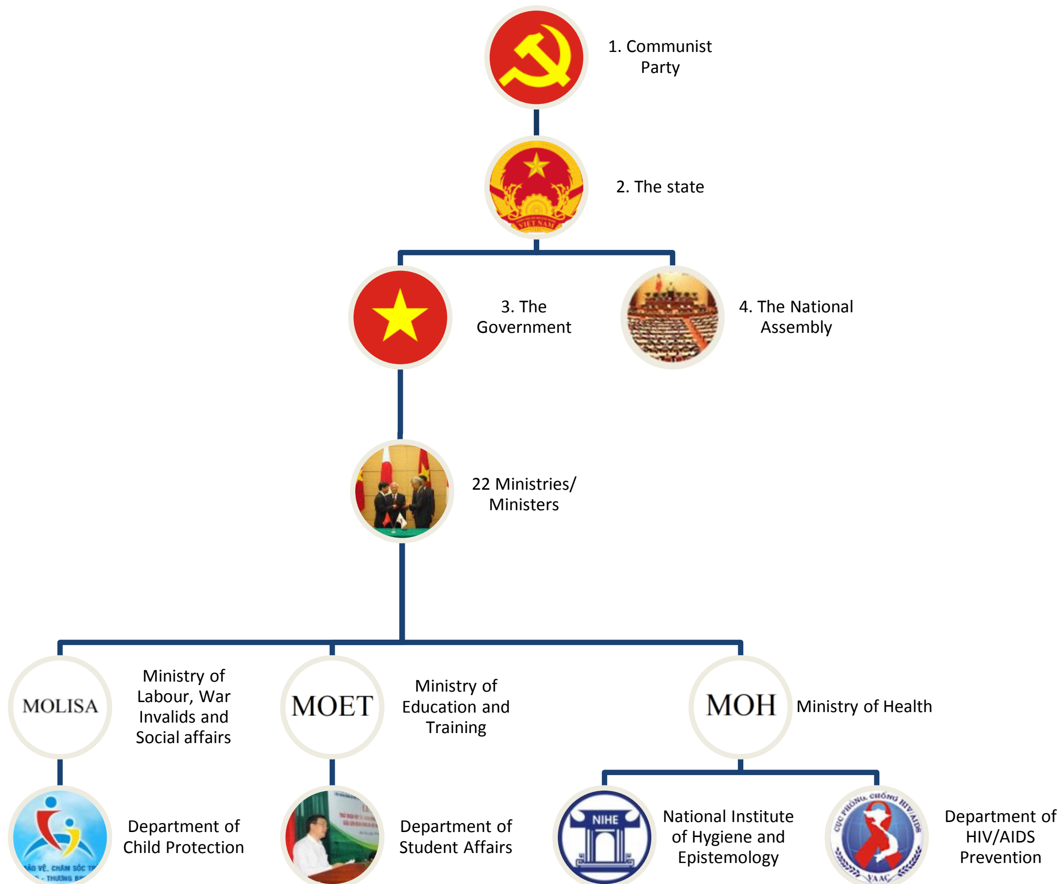

Figure 1.1 the Political System of the Socialist Republic of Vietnam

The Socialist Republic of Vietnam is a one-party state, led by the Communist Party of Vietnam. The state consists of the National Assembly, Vietnam's head of state; the President and the government. The National Assembly is like a 500-member parliament representative of the people and has legislative power, while the President and the government have executive power. In turn, the Prime

Minister is the head of government and governs Vietnam together with Vice Prime Ministers and ministers of twenty-two different ministries such as the Ministry of Health and the Ministry of Education and Training. Each Ministry has their own departments as shown above (Dao, 2016).

This outline is a simplified structure of the state apparatus. Most ministries, departments and the juridical system have been excluded. However, the governmental agencies which are relevant for this study have been included in the figure above. For the three ministries in focus, abbreviations are written within the circles because these are used in the analysis. I have interviewed people working within the department of child protection, student affairs, HIV/AIDS prevention and the National Institute of Hygiene and Epistemology. These departments and the three ministries MOLISA, MOET and MOH work preventative together with UN organizations, international NGOs and local NGOs in order to prevent stigmatization of people living with HIV/AIDS in Vietnam. What their work entails will be presented in the analysis.

3. Literature review

The following literature review provides an overview of the current research about access to education for children living with HIV. The literature review begins with a section about the right to education. Thereafter, earlier research about the HIV/AIDS epidemic is presented.

3.1 The right to education

> Education is the most powerful weapon you can use to change the world – Nelson Mandela 2003

The United Nations Declaration on human rights states that everyone has the right to education. It declares that elementary school should be free and compulsory and higher education should be equally accessible to all (UN General Assembly, 1948). During the past century, education has become one of the most important

developmental strategies around the world. Amartya Sen (2001) argues that education is the means and the end to development. To achieve universal primary education was one of the MDGs. Countries such as Japan has gained vast economic growth the past decades and made significant investment in universal education. As a result, education has become a method of poverty alleviation. For poor communities sending their children to school provides a way to escape poverty (Amartya Sen, 2001).

A lot of efforts have been made to increase access to education by promoting the right to education in international law. Even though everyone has the right to education, access to education varies considerably. Growing inequalities negatively affect education. Nowadays, about 124 million children do not attend primary education. Gender inequalities are prominent and the majority of out-of-school children are girls. As a result, approximately two thirds of the 785 million illiterate people worldwide are women (Colclough, 2014).

Unequal access to education is a huge concern for development but also for Social Work because lack of education causes social exclusion and other social problems. Poverty and child labor are two of the main reasons why children do not attend primary school. UNDP's Human Development Index (HDI) is an alternative way to measure poverty. HDI measures poverty in terms of educational attainment instead of measuring GDP (White, 2014:112).

Education plays a fundamental role in human, social and economic development. Investments in education, healthcare and nutrition are examples of human capital development. Healy states "sustainable development ultimately depends on enhancing people's own capacities to improve their own lives and to take more control over their own destinies" (Healy, 2008:281).

3.2 The HIV/AIDS epidemic

Worldwide, the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) has claimed millions of lives. HIV is a virus that deteriorates the immune system. Fatigue, infections and weight loss are common

symptoms. After a number of years without treatment the infected person has AIDS when the body no longer can fight off infections. There are many misconceptions about the spread of HIV. Sabin, McNabb and DeSilva clarify this by stating:

> HIV is transmitted through the exchange of body fluids, including semen, vaginal secretions, blood and breast milk. Worldwide, most people contract HIV from sexual contact, although needle-sharing, blood transfusions and breastfeeding are responsible for many infections (Sabin, McNabb and DeSilva, 2014:642).

In 2014, approximately 37 million people were living with HIV/AIDS (PLWHA) globally. Sub-Saharan Africa is the most affected area. Yet, there are high numbers of people living with HIV and AIDS in Russia, Mexico, Brazil and South East Asia as well (UNAIDS, 2015). The HIV virus can be suppressed with antiretroviral therapy (ARV) which is available in most countries. People with HIV can live many years with the use of antiretroviral therapy. However, access to treatment is limited in Sub-Saharan Africa due to lack of resources and other factors which will be discussed below (Sabin, McNabb and DeSilva, 2014:642).

3.3 Access to healthcare for children

Globally, there are about 3.2 million children living with HIV/AIDS (UNAIDS, 2016). The availability of life-saving antiretroviral therapy has increased in developing countries the past decades. This treatment makes it possible for HIV positive children to stay healthy and live for a long time (Baxen and Haipinge, 2015:238). Yet, only 34 percent of children qualified for treatment are accessing antiretroviral therapy worldwide. There are a number of different barriers for children to access treatment.

Firstly, lack of knowledge about HIV hinders treatment. For example, one study from Mozambique shows that some respondents believed that HIV can only be healed with traditional rituals since the disease have spiritual causes. These beliefs

cause inter-generational conflicts. Grandmothers might object to treatment for children and prefer traditional healing. Mothers of children with HIV might instead have the desire to seek antiretroviral therapy at healthcare clinics. As a result, treatment is available but cultural practices might limit the accessibility of healthcare. As a matter of fact, HIV fuels gender-based issues since women are often the primary caretaker of children (De Schacht et al., 2014:4, 10).

Secondly, fear of disclosure limits children's access to healthcare. In Mozambique, women are hesitant to seek treatment for their children because their husbands might find out about their HIV status and force them to move out (De Schacht et al, 2014:11-14). This is a major issue in Kenya as well. Treatment might therefore be avoided because the women are often financially dependent on their husbands (Bemia-Sofie et al., 2014:558).

Thirdly, transportation is a major problem in accessing antiretroviral therapy even though healthcare itself is free. It is expensive to travel to hospitals, especially because antiretroviral therapy requires regular healthcare visits over a long duration of time. People who live in rural places are particularly affected by these barriers (Busza et al., 2014:2). Lastly, lack of social support and risk of stigmatization severely limits access to life-saving treatment. Besides, some people still view HIV as a death sentence and do not seek treatment as a consequence (De Schacht et al., 2014:11-14).

Moreover, antiretroviral therapy requires a balanced diet and medication must be taken on time each day together with food. Fatigue, nausea and rashes are common side effects of this treatment even though the treatment improves the immune system. Namibian school children express their experiences of taking antiretroviral therapy in an article by Baxen and Haipinge (2015). One child explained that the medication made him sick if he took it on an empty stomach. Another young student expressed that there was not always food available at his house and he could therefore not take his medication on a regular basis. Highly

active antiretroviral therapy is more effective and has only minor side effects. Yet, the availability of this type of drug differs among countries (Baxen and Haipinge, 2015:240).

Brazil has significantly improved their healthcare system by providing universal access to highly active antiretroviral therapy since 1996. Expensive in-patient care has been replaced with less expensive ambulatory-based care. As a result, mortality rates have been cut by 50 percent and 80 percent of hospital admissions has been reduced. The quality of life for children with HIV has also improved considerably (Abadia-Barrero and Castro, 2006:1220).

3.4 HIV and access to education

Another growing issue in Vietnam is children affected by HIV/AIDS. Today, there are about 500.000 children affected by HIV/AIDS, even though only about 5000 of them are infected with HIV. Children affected by HIV/AIDS entail a larger group of children, including children who live with an HIV-positive family member, children whose parents have died from HIV/AIDS and at risk children due to orphan hood, drug use, sexual abuse or trafficking. These children are often abandoned due to socio-economic problems. In many cases their parents have died from AIDS (UNAIDS, 2014).

There are anti-discriminatory laws in Vietnam in order to ensure equal rights to healthcare, education and employment. A number of NGOs and governmental agencies work to implement these policies through different projects. Nevertheless, these laws are not functioning due to public stigma concerning HIV/AIDS. As a matter of fact, Vietnamese children with HIV have been excluded from the public school system because of parental protests (Boggiano et al., 2014:171). Similarly, research from the United Kingdom, Croatia and Namibia show that children living with this illness face discrimination within public schools (Baxen and Haipinge, 2015:238; Rowson, 2012:383; Starcević and Begovac, 2005:697).

The article titled ‘Parental attitudes regarding the integration of children living with HIV/AIDS into public schools in Hanoi, Vietnam’, conducted 60 interviews with parents in Ba Dinh and Ba Vi Districts. Lack of information about HIV transmission is the main reason why parents oppose HIV-positive children to enroll into public schools. These parents wanted to protect their HIV-negative children from infection (Boggiano et al., 2014).

Nevertheless, the study found that 56 percent of the interviewed parents were supportive of integration if parents, teachers, and students are told about the children’s health status. For instance, one mother from Ba Vi District emphasized that there is no risk of HIV transmission at school. Yet, 25 percent of respondents opposed integration of HIV-positive children into public schools. Mainly because they believed that HIV could be transferred by touching or sharing food. One father from Ba Dinh District expressed fear about children hurting themselves during play and infecting others (Boggiano et al., 2014:178). In fact, there is no documented case of HIV transmission as a consequence of contact with spillages of blood because there is no transfer of body fluids between people. Besides, contact with tiny quantities of HIV in dried blood does not cause infection.

Additionally, some parents expressed concern about the low number of teachers in school being unable to prevent the risk of transmission. Other parents were worried about HIV-positive children being stigmatized and ill-treated in public schools. A mother from Ba Dinh District said that disclosure about HIV-status is not necessary because it creates stigma, while another respondent believed that children living with HIV should have private classrooms. One mother from Ba Vi District distinguish between ‘good’ and ‘bad’ children based on how they had acquired HIV. Children born with the infection is perceived as innocent while adolescents who were infected through drugs or sexual contact should not be allowed to enter schools according to this respondent (Boggiano et al., 2014:178-180).

As a result, AIDS is associated with immoral behavior. However, Baxen and Haipinge (2015) disagree to some extent with the statement above and argue that children with HIV are stigmatized regardless of how they were infected. Children are blamed even though they had no control over the situation in which they were contracted with HIV. For example, one Namibian boy was bullied in school after he contracted the virus through rape. Other children at school called him 'AIDS monster'. The boy expressed "it hurt me so much because I did not get AIDS because I wanted it but because someone raped me" (Baxen and Haipinge, 2015:242). This is a clear example of how HIV-related stigma causes ostracism, victim blaming and denial of human dignity. The social processes of stigmatization and discrimination will be discussed in further detail within the theoretical framework below.

In connection, Brazilian children have been denied the right to education due to HIV-related stigma. Parentless children living with HIV are particularly stigmatized. However in recent years extensive resources have been allocated to support this target group. As a consequence, the 'AIDS-orphan' label might bring social advantages which are not accessible for other children living in poverty. Parentless children with HIV receive extensive support from non-governmental organizations which provide healthcare, food, education and housing. Profound levels of poverty exclude many healthy children from accessing education as well (Abadia-Barrero and Castro, 2006: 1221). Most Brazilian children receive private primary and secondary education. Private schools outperform public schools. Poor children's access to higher education is therefore severely limited. HIV-related stigma intensifies these inequalities.

3.5 Stigma reducing interventions

As mentioned earlier, stigma is a major challenge for children affected by HIV/AIDS to access education. Therefore, I want to present earlier research about different stigma reducing interventions. Based on earlier research four types of

stigma reducing interventions are identified; *information-based, contact with affected groups, coping skills and counselling* (Brown et al., 2003:23-25). Information-based interventions and interventions which involve contact with the affected groups aim to raise awareness and acceptance. Information-based strategies involve rising awareness through presentations, campaigns and group discussions. Contact with affected groups involves face-to-face interaction between communities and people living with HIV.

These strategies increase people's knowledge about the spread of HIV. Stigma is in fact often caused by ignorance (Boggiano et al., 2014:181). Research from Israel, Tanzania, United States and Jamaica suggest that these interventions increase tolerance and understanding. However, Abadia-Barrero and Castro (2006:1226) argues that these interventions have limited effect because they do not change the experience of stigmatized persons, only the attitudes of unaffected people. The changes in public attitudes have been mostly short-term and community-based.

Instead, assuring access to highly active antiretroviral therapy through governmental programs reduces stigma significantly. This type of therapy increases well-being and makes people living with HIV healthy-looking. It thereby changes public perceptions of HIV as well (Abadia-Barrero and Castro, 226:1226). Highly active antiretroviral therapy allows people to fight against stigmatization and structural oppression. In addition, coping skills and counselling are strategies directed towards people living with HIV. These interventions aim to help people to adapt to and cope with HIV-related stigma. For instance, role-play, reframing techniques, counselling sessions and support groups (Brown et al., 2003:25). These strategies have shown positive results in Zimbabwe, where disclosure of HIV-status has increased. One study in Tanzania combined information and coping skills in an intervention for primary school children. Information together with group discussions and role-play made a significant change in the children's attitudes concerning people living with HIV (Brown et al., 2003:11).

4. Theoretical framework

Theorizing seeks to provide support and interpretations of research findings. Social constructivism is used in this thesis together with Sontag's (1989) work on metaphors, Goffman's (1963) theory of stigma, Bourdieu's (1986) theory of capital and Foucault's (1977) concept of power. This is the most useful theoretical framework because it provides important insights and different perspectives of the social and cultural barriers in access to education for children affected by HIV.

For example, I chose not to use Becker's labeling theory since I want to focus on social and cultural barriers to education, instead of emphasizing psychosocial consequences of HIV-related stigma (Becker, 2008). In fact, I add Bourdieu's theory of capital and Foucault's work on power in order to move away from the individualistic perspective of stigma. The power and class perspective adds depth and gives structure to the analysis and a more accurate picture of the complexity of stigma.

4.1 Ontological and epistemological standpoint

This thesis applies a social constructivist view of reality, knowledge and connection to the research. Berger and Luckmann are the pioneers of social constructivism and the main argument is that social reality is socially constructed (Luckmann, 2008:282). HIV is a medical disease but the reactions to and interpretations of the disease must be understood against the background of social and cultural conditions. Social constructivists emphasize the social and cultural context in order to understand certain phenomena. In terms of ontology, social constructivism entails that the researcher is a constructive part of the research and that reality is constructed of our knowledge. In contrast to positivism, this theory goes beyond objective facts. Instead, social constructivism studies unobservable entities such as social structures. This theory provides a deeper understanding of the context and system of oppression that HIV generates through the process of stigmatization (Hekman, 1983:211).

4.2 The social construction of AIDS

AIDS is not only a virus it is also a social construct and associated with a number of metaphors. I chose to use Sontag's (1989) work on HIV and metaphors for that reason. The metaphor concept provides a linguistic dimension to my analysis which corresponds well with Goffman's (1963) concept of stigma. In 1982, the first case of AIDS was discovered. With space suits, doctors had no idea how to treat the virus. Because of the limited knowledge about the cause and spread of the virus mass propaganda caused public fear and paranoia. AIDS was associated with death and immoral behavior such as promiscuity and drug abuse. In comparison, cancer is seen as a random cause while AIDS is connected to guilt and personal fault. Another metaphor of AIDS is a slow and painful death. This metaphor causes further terror to a 'death sentence'. The construction of AIDS separates different groups from each other, such as the sick and the healthy and 'at risk' groups (Sontag, 1989:81).

It is 27 years ago Susan Sontag wrote the book *AIDS and its metaphors*. Nowadays, highly active antiretroviral therapy has transformed HIV from a death sentence to a "manageable chronic disease" (Abadia-Barrero and Castro, 2006:1226). Therefore, people living with HIV look healthy and can avoid opportunistic infections. They can live normal lives. In spite of this, HIV is still associated with immoral behavior and unhealthy appearance. AIDS is connected to 'plague', weight loss, disfigurement and skin rashes. As a result, AIDS is viewed as a repulsive illness with dehumanizing symptoms. In addition, AIDS is tied to the so called 'third world' and thereby associated with poverty and ethnicity. In the United States there is a high HIV prevalence among African-American and Hispanic communities (Sontag, 1989:74).

This is mainly because of overrepresentation of ethnic minorities in prisons and poor communities. Previously, European propaganda claimed that 'the general

population' was safe from contracting HIV. Yet, Sontag (1989:82) argues that the general population actually refers to middle-class, heterosexual, whites. The myth functioned as demarcation between 'us' and 'them'. This will be explained further below.

4.3 Goffman's concept of Stigma

The concept stigma has been chosen in order to understand the social reaction towards children living with HIV. In 1963, Erving Goffman wrote about the concept of stigma in his book *Notes on a spoiled identity*. Stigma is "the process by which the reaction of others spoils normal identity" (Nettleton, 2006:95). Stigma is an exceptionally degrading, offensive and patronizing character trait. People are categorized and socially stereotyped beliefs are attached to these categories. I chose Goffman's (1963) work on stigma because he emphasizes morality and that stigma is about degradation of a person's moral character. For example, if a person is categorized as a criminal he or she might be regarded as dangerous or untrustworthy as a result. Degradation of the person's perceived morality follows. This kind of stereotyping is based on metaphors which cause stigmatization and social rejection (Parker and Aggleton, 2003:19). Stigmatization often leads to social exclusion and humiliation. This process is explained by Abadia-Barrero and Castro (2006:1221):

> The social construction of AIDS-related stigma has been nurtured by historical components including social fear, ignorance, anxiety, lack of knowledge, denial, shame, taboo, racism, xenophobia, and moral judgments, and by misleading metaphors like death, punishment, crime, war, horror, otherness, and shame.

Stigma is caused by society's norms of what is considered 'normal' and 'abnormal'. Each social group has adopted social codes which construct rules about how an individual should look and behave to fit in. Based on these norms the stigmatized individual is not perceived as fully human and thereby

discriminated. Discrimination could in turn diminish various social opportunities such as education and employment for instance (Becker, 2008:1; Goffman, 1963:115, 139). Stigmatization could also lead to self-stigma. Self-stigma involves the process when individuals distance themselves from other people in order to avoid discrimination. As a result, self-stigma leads to feelings of shame, self-hatred and isolation (Goffman, 1963:7).

4.4 Bourdieu's concept of Capital

Economic, cultural and social capital is interlinked. In order to generate economic capital one must cherish one's social and cultural capital. This theoretical perspective is relevant for this thesis because of the relationship between education and social standing. For example, Bourdieu (1986:85-87) writes about *cultural capital*. He claims that unequal access to education and unequal school achievements among children stems from *class distinctions* and *class fractions*. For example, rapid economic growth often leads to substantial inequalities in income, education and healthcare. The growing inequalities intensify class fractions and the importance of one's social standing (Parker and Aggleton, 2003:19).

Social capital is constructed of social obligations, which can be converted into *economic capital*. Economic security often lies in the family and social network within developing countries. Strong social connections with extended family and friends are therefore vital for capital accumulation. Culture is highly relevant in connection to social capital (Bourdieu, 1986:84, 89). In connection to stigma, Goffman's theory has been criticized of being individualistic. Viewing stigma as individual behavior makes more sense in western countries. Nonetheless, in the context of developing countries stigma is clearly a social and cultural phenomenon linked to structural oppression (Parker and Aggleton, 2003:19). Therefore, Bourdieu's work provides another dimension of this phenomenon.

4.5 Bourdieu's and Foucault's concept of Power

In terms of oppression, stigma should be analyzed in connection to power and culture. Power is not emphasized by Goffman. In order to add an emphasis on power I add Foucault's work *Discipline and Punish* to my theoretical framework. Even though Foucault does not mention stigma he brings an additional perspective of the cultural production of deviance caused by unequal power relations. According to Foucault, *subjectification* occurs in different knowledge systems which are controlled by regimes of power (Foucault, 1977).

This is tied to Bourdieu's work as well. Bourdieu claims that all practices are motivated by self-interests to increase social distinction and demarcations between groups. Inequalities are legitimized with the use of power. Similarly, the history of stigma should not be forgotten. Stigma arises in specific contexts of culture and power. Also, how stigma has been used by states and groups to reinforce inequalities. *Cultural socialization* entails the competition between groups for status and economic capital (Bourdieu, 1986:84, 89; Parker and Aggleton, 2003:17).

Stigma is the most useful theory in order to analyze access to education for children living with HIV in Vietnam. Since stigma is a major problem. Besides, to investigate the social phenomenon of stigma concerning access to education is the aim of this study. Yet, the concept of stigma has its limitations. HIV-related stigma focuses on the individual level and fails to incorporate the socio-economic, cultural and political context. Stigma creates discriminatory processes which severely damage the person's well-being.

Nonetheless, stigma has a strong connection to power relation and structural inequalities. I have chosen to combine stigma with the work of Bourdieu and Foucault in order to expand my theoretical lens to larger social and political issues. Children living with HIV in Vietnam face a number of barriers due to

their multiple layers of vulnerabilities. Social differences and intersectionality such as ethnicity, nationality, gender, sexuality and class impact everyday rights. Stigma is multidimensional and cannot be viewed as a separate process but rather a number of simultaneous processes. From this perspective, stigma creates social processes which reproduce inequalities and reinforce exclusion of already marginalized groups (Abadia-Barrero and Castro, 2006:1221). Together Goffman, Bourdieu and Foucault's work offers a multidimensional perspective of "culturally constituted stigmatization as central to the establishment and maintenance of social order" (Parker and Aggleton, 2003:17).

4.6 Empowerment

Empowerment is a central concept in social work. Empowerment has many different meanings. Yet, in this thesis the meaning of *empowerment* is about the capacity of individuals or communities to exercise control and power over their own lives. When people are in control of their own lives they are able to help themselves, reach their goals and find solutions to their problems.

Empowerment is about being free of oppression and structural violence which hinder *self-efficiency, independence* and cause *disempowerment*. In social work, empowerment practice involves enabling people to fight injustice and improve their quality of life. Empowerment is connected to *participation*. This concept entails communities participating in development projects or self-help groups. Empowerment is also linked to emancipation and advocacy; "emancipation means liberating a person from oppression or undesired physical, legal, moral or spiritual restraints and obligations" (Adams, 2003:6).

Participatory social work is a practical method which enables people to describe their problems and finding ways to solve these issues themselves. Nowadays, empowerment is a critical, right-based and an anti-oppressive practice. However, it is important to remember who has the power to create those participatory

‘spaces’ and who has not. Often, *participatory* social work actually leaves little space for full-participation. As a result, the concepts of empowerment and participation must be used critically. In order to empower people, one must be aware of how unequal power relations influence the process of empowerment. Besides, the client-professional relationship is inevitable unequal. Lastly, this theoretical perspective is relevant for this thesis because empowerment is about supporting vulnerable groups and enhancing their capacity to exercise their rights. Thus, empowerment is central to the aim of this thesis (Adams, 2003).

5. Methodology

5.1 Qualitative study

This thesis applies a qualitative research design in order to answer the research questions. Qualitative research is most appropriate in this study because qualitative research seeks to produce nuanced descriptions of people’s opinions and experiences (Kvale and Brinkmann, 2009:28). In fact, earlier research has mostly applied qualitative methods within this topic (For instance see Wattradul and Sriyaporn, 2014).

Quantitative and qualitative research strategies are two different approaches to social research. A qualitative study is a research strategy which focuses on words and meaning. In contrast, quantitative research employs quantification and focuses an numbers, while qualitative research emphasize words, linguistic and underlying causes/meanings of social phenomenon. Yet, there are deeper differences between the two research strategies. For example, qualitative research leans towards a constructivist ontological orientation while quantitative studies favor objectivism (Bryman, 2012:36).

I chose to conduct a qualitative study because a quantitative research strategy is not suitable for this study. My study aims to gain a deeper understanding of a

social phenomenon which is central for qualitative research. Another preferable aspect of qualitative research is that the point of view of participants is highlighted and the researcher is viewed as an integral part of the research process. However, there is critique against qualitative research. Some argue that findings from qualitative research are too subjective and neither replicable nor generalizable. Nevertheless, the aim of qualitative research is not to produce hard reliable numerical data, but rather rich deep qualitative data (Bryman, 2012:405-408). Semi-structured interviews with practitioners bring in-depth knowledge about how stigma creates barriers for HIV-positive children to access education.

The aim of this study is to gain a deeper understanding of the stigma and barriers which children with HIV face in regards to education in Vietnam and to analyze the strategies practitioners implement to promote equal rights to education and prevent stigmatization. The study was carried out in the capital of Vietnam, Hanoi. Hanoi was chosen based on convenience. During my internship I lived in Hanoi and was able to find interviewees in Hanoi through my internship placement. Social contacts are important during research and I met a few people during my internship that later participated in my study. Besides, eight out of the top ten provinces with the highest HIV prevalence are located in the north of Vietnam (UNICEF, 2010:124).

5.2 Data Collection

5.2.1 Sampling

Practitioners working within areas of education and/or healthcare in Hanoi were the target group in this study. The focus on expertise knowledge makes this research expert-oriented and solution-focused. On the other hand, one could argue that the real experts of any social problem are affected groups. However, people affected by HIV/AIDS in Vietnam are highly vulnerable and difficult to reach.

Besides, one must keep in mind that research could harm vulnerable groups. This will be discussed further in the ethical considerations section below.

Therefore, I have chosen to focus on expertise knowledge based on convenience and ethical considerations. Together with my internship supervisor I selected the organizations and government agencies which were of use for my thesis. I sent emails to different non-governmental organizations in Hanoi and asked a few people if they knew any experts that could participate in my study. My internship organization helped me translate an information letter[2] into Vietnamese and sent it to three different government agencies via post.

My internship supervisor was the head of the department of child care and protection for 17 years. Therefore, many of his former colleagues currently work within governmental departments. My supervisor supported me by signing the information letter and calling informants. Another colleague of mine also helped me call informants. Their help helped me significantly. In fact, my interpreter Minh helped me get in contact with one interviewee as well.

As a result, non-probability *purposive sampling* and *snowball sampling* is used in this thesis. This sampling method involves selecting informants based on the research purpose. Snowball sampling entails asking interviewees if they know anyone else who could participate in an interview. As such, each informant helped me find additional interviewees. This sampling method creates a non-probability sample which means that the sample does not represent the research population (Bryman, 2012: 418).

Accessibility and the expertise of the interviewees were the two most influential factors in constructing the sample. The selection criteria of the informants were limited. Those who agreed to partake in the study were interviewed. People working in the relevant fields were contacted. Also, the interview questions were

[2] See appendix I

sent to the participants in advance. Two persons working for international organizations responded that they did not have sufficient knowledge of the topic to participate in my study. This strategy helped to increase the relevance and quality of interview data.

Most informants in this study have a master degree or a PhD in a health related field such as Medicine or Public Health. The average age of the interview participants is 44 years. The majority of the interviewees are senior researchers, senior program officers, executive directors or having top positions in governmental departments.

5.2.2 Interviews

To gather information about the informants' opinions and experiences, I conducted nine in-depth *semi-structured interviews*. The face-to-face interviews were conducted the 3rd – 24th of December 2015 at the informants' workplaces in Hanoi and lasted for 40-80 minutes each. Before each interview I explained the purpose and aim of my study and informed the interviewees about ethical considerations. They were given the opportunity to terminate the interview and avoid answering specific questions. After signing an informed consent form, the informants were asked ten open-ended questions based on an interview guide[3].

An interview guide gives structure to qualitative interviews. This is important in order to find similarities and differences in interview data. Yet, open-ended questions makes it possible for informants to speak freely and steer the interview in the direction they want (Kvale & Brinkmann, 2009:132). For these reasons, semi-structured interviews were the best option for this thesis. The interview guide was developed using three themes in reference to the research aim. These themes consisted of *challenges, stigma/discrimination* and *strategies.* Probing and interpreting questions were asked during the interview for clarification. Similar

[3] See appendix II

questions were asked to check for consistency. This increased the level of validity and reliability.

5.2.3 Translation

Four interviews were conducted with the use of an interpreter. My interpreter Ms. Minh is a professional translator who has 15 years working experience form organizations and embassies in Hanoi. Minh has previously worked for the Embassy of Australia and the Embassy of Sweden. During each interview Minh translated word-by-word and conducted simultaneous translation. This meant that the informants could speak freely without any pause and Minh would translate simultaneously.

First, I asked a question in English then the interpreter asked the same question in Vietnamese. Secondly, the Vietnamese answer from the interviewee was translated into English. The interview guide was also translated into Vietnamese. All informants were given an interview guide in Vietnamese to read during the interviews. In fact, the interview guide was sent to the informants in advance. This strategy made it possible for the interviewees to prepare before the interviews.

On the other hand, it could be argued that spontaneous answers increase validity. Yet, the interviewees' preparation increases the flow of the interview and saved a lot of time. For example, a few informants had prepared notes before the interview. One could argue that the participants became more comfortable, prepared and able to provide more deep and detailed answers. After each interview an interview protocol[4] was written by the researcher. The interview protocol was used in order to take notes and document thoughts about the interview situation. All interviews were audio recorded using a smartphone. During the fourth interview the recoding was lost due to technical problems. Instead, notes were used to transcribe the interview. As a consequence, no quotes

[4] See appendix IV

could be made from this interview. Yet the main ideas were documented. The remaining interview recordings were transcribed without technical error.

5.2.4 Data transcription

The interviews were recorded and I transcribed them myself. Ideally, the interview recordings should have been sent to Minh for transcribing and translation. However, due to financial constraints I transcribed them myself. Certainly, this has a negative impact on validity. Yet, Minh translated directly word-by-word so each and every Vietnamese word has been translated into English and thereafter written down in my transcripts. The validity threats from this method are compensated by the use of a highly skilled professional interpreter and the word-by-word translation. As a result, the translated interviews uphold high quality and contain minimal errors.

5.3 Ethical considerations

The purpose of ethical considerations is to protect research participants from harm. Besides, research needs to generate useful findings in order to be considered ethical. Ethical considerations were protected throughout this inquiry. There are four ethical principles which all research must uphold, these are; *transparency, confidentiality, autonomy and self-determination* (The Swedish Research Council, 2002).

Firstly, research must be *transparent*. This means that the participants in the study need to be informed about the purpose of the research. This principle also entail that the researcher cannot hide sensitive questions. Thus, participants need to know in advance what topics will be discussed during the interview. In this study, I have ensured transparency by sending the interview guide to the informers before the interview took place. With the use of this method, the informers were able to decide whether or not the interview questions would expose them to harm

or not. Special considerations were made in regards to the cultural and political context when developing the interview guide (The Swedish Research Council, 2002).

Secondly, *confidentiality* means that the participants' identity and personal information must be kept anonymous. This information must be kept in a secure place and cannot be shown to others. Confidentiality is closely related to secrecy, which involves ensuring that others cannot know about their personal information. Likewise, it is prohibited to use quotes in the research which can reveal the identity of the interviewee. Therefore, the informants are referred to as I1, I2, I3 etc. in my analysis. Quotes which could reveal the informants' identity were left out. These code names were used in the text as well in order to clarify and show that all informants were heard in my analysis. This also makes it easier to distinguish between my interpretation and the informants' statements.

Thirdly, *autonomy* entails being truthful about the usage of interview findings. The participants must be ensured that the interview material as well as their personal information will only be used for scientific purposes. Lastly, *self-determination* is essential within all research. This principle is about ensuring voluntary participation. Participants are able to choose which questions they want to answer and end the interview at any time without reason. The researcher must inform the participants that non-participation will not bring any negative consequences. In terms of self-determination, one must consider the exploitive nature of research and pay special attention to vulnerable groups (Bryman, 2012:140).

Before each interview the informants signed an informed consent[5] which has been developed based on The Swedish Research Council's (2002) guidelines. In the initial email, informants were sent an information letter[6] which states the ethical

[5] See appendix II
[6] See appendix I

considerations of my research. The informants were informed in writing and verbally that:

- the researcher ensures secrecy and confidentiality
- transcripts are anonymous
- transcripts and quotes cannot be connected to their identity
- the thesis has only scientific purposes
- consent is completely voluntary:
- the interview can be terminated at any time without reason
- individual questions can be rejected
- no negative consequences occur from non-participation

There are several ethical benefits in choosing to interview experts instead of affected groups. The informants in my study are not in a vulnerable position which limits the risk of harm caused by my inquiry. Also, I can guarantee voluntary participation to a greater extent compared to vulnerable groups who are paid for participating in studies. The informants in my research were given sweets as a symbolic gift. The possible harm of my study for children living with HIV in Vietnam is also minimal since most of the informants do not work directly with children. The majority of my informants have administrative or managerial positions within NGOs or government agencies. Nevertheless, I have considered the ethical implications of interviewing people who work directly with vulnerable children.

5.4 Reliability and validity

Reliability and validity is about research quality and credibility. Reliability and validity is different within quantitative and qualitative research. The quality of qualitative results must be measured differently from quantifiable data. Quantitative research findings are often constructed in artificial settings which make it possible to replicate the study. Subjective data makes it difficult to

measure the reliability of research findings. Generalizability is also limited in qualitative research because of small samples and social settings. This is the case of this study. The possibility to generalize the findings of this study is limited because my sample is not representative of the research population. The aim is not to generalize findings, but rather make theoretically informed interpretations which provide contextual understanding (Bryman, 2012:408).

Trustworthiness is an alternative criterion for evaluating qualitative research. Trustworthiness is divided into four factors; *credibility, transferability, dependability* and *confirmability* (Bryman, 2012:390). *Credibility* is connected to internal validity. The findings of this study are credible because the empirical data is presented in quotes together with my interpretations. This allows researchers to evaluate the validity of conclusions. My results correspond well with earlier research which also adds to credibility of findings. These comparisons are made in the last section of the analysis. Besides, my research aim has been fulfilled and ethical considerations have been made.

Additionally, *transferability* or external validity in other words, has been achieved by presenting thick descriptions of the studied social phenomenon. These rich descriptions are contextual but might find support within other contexts as well. This provides the possibility for readers to make judgements and evaluate the transferability of findings (Bryman, 2012:391).

Moreover, *dependability* is connected to reliability which was achieved in this thesis by presenting a transparent research process. All threats to reliability have been discussed. For example, the risks associated with translated interviews, transcribing and recording errors and possible biased interpretations. These possible threats have been identified and discussed. No research errors have been hidden from readers to take part of. This is connected to *confirmability* and objectivity (Bryman, 2012:392).

Objectivity is generally low within qualitative studies, but confirmability can be reached by being a trustworthy researcher. This entails that the researcher limits bias and personal values to influence findings. However, in this thesis social constructivism is applied as the ontological orientation. Social constructivism recognizes the researcher as an active part of the research process. Yet, self-reflection is important in order to be aware of personal bias and limit its influence. This has been considered in this study by presenting different interpretations (Bryman, 2012:392).

5.5 Method of analysis

5.5.1 Meaning coding

In my study I used meaning coding and interpretation. This strategy entails reading the interview transcripts as a whole, then reading each transcript separately in detail. After reading, I started coding my interview transcripts. I attached key-words to specific sections which capture the direct or underlying meaning of the statements. For example, stigma was one of the key-words. I tried to keep the codes unbiased since I wanted to keep the results close to my data and identify both direct and underlying patterns. Contradictions among the interview statements were also identified. Codes were short and precise and able to capture the richness of the interview descriptions (Kvale & Brinkmann, 2009:203).

Thereafter, I created categories by bringing codes together. At this stage eight themes where formed. I continued with conceptualization which involved changing different themes and labelling these categories. For each theme I would extract quotes from my transcripts and group them accordingly. Then thorough my analysis I described and interpreted each theme in light of my theoretical concepts as well as the connections between the themes. I divided the analysis into two main parts; challenges and strategies, in reference to my aim and research

questions. The theoretical perspectives are: Metaphors, stigma, capital, power and empowerment.

5.5.2 Hermeneutics

Hermeneutic and the hermeneutic circle were applied in this study to give further depth to research findings. Hermeneutics is a perspective which seeks to understand and interpret the meaning of texts such as interview transcripts. The hermeneutic circle aims at a deeper interpretation of meaning. This circle entails a back-and-forth process of analyzing parts of the text separately and then analyzing the text as a whole, then going back to view the findings from specific perspectives again (Kvale & Brinkmann, 2009:210).

This was conducted by analyzing specific themes and theoretical concepts separately then interpreting them together as one entity. With the use of hermeneutics, the social and cultural context was highlighted. Hermeneutics gives attention to details which helps in the quest to reveal underlying meaning. It is important to hear what the interview participants are saying but also what they are not saying. Thereby, reading between the lines (Bryman, 2012:560).

6. Analysis

To recall, the main research question and sub-questions are formulated as follows:

- *How do practitioners work in order to prevent stigmatization and ensure equal rights to education for children living with HIV in Vietnam?*
- *According to the informants, what are the main challenges for children living with HIV and how does stigma influence the children's access to education?*
- *What cultural and social meanings are tied to the social construction of HIV in Vietnam?*
- *What are the social and cultural barriers in preventative work and access to education for children living with HIV?*

- *Is the practitioners' work aimed at the children's adaptation and coping with stigma, or focused at developing knowledge and awareness/ understanding/ acceptance among the public and general population?*

6.1 PART 1: Challenges

6.1.1 Social construction of metaphors

To start off my analysis I will begin with analyzing the social construction of metaphors. HIV is not only a virus it is also a social construction with many different social meanings (Sontag, 1989). Accordingly, HIV/AIDS is used as a metaphor which the informers are aware of. From a historic perspective, the Vietnam War and globalization has a significant impact on Vietnam's response to the HIV epidemic.

Propaganda

Nevertheless, before treatment HIV was a deadly disease and the government spread a lot of propaganda about this topic (I9). Propaganda posters have linked HIV to death, disfigurement, drug use and prostitution. Most informers mention the impact of these posters in creating HIV-metaphors. Such metaphors are deeply rooted in the public's perception and involve 'death', 'social evil', drug use and sex work (I2, I3, I4, I6). People living with HIV are perceived as 'bad people' and 'unethical' (I1, I5). One informant explains that the public cannot be blamed for this attitude:

> In the past we also cited in posters about HIV together with drug use and sex workers and bones, sculls and death. So now everyone thinks that if you get HIV then you are either a drug user or engaged in sex trade. That is past down over time. I think it's a very terrible co-product of communication (I5).

In this quote the informant states the consequences of propaganda. Based on my interpretation, the propaganda was used by the government to warn people about the virus. Yet, the propaganda created HIV as a metaphor. As such, HIV is still associated with death, sex work and drug use. Besides, another interviewee points out that the mortality of children living with HIV is very high. If there is no treatment most of them will die before they reach 5 years old (I9). Life-saving antiretroviral treatment has changed this. Two participant met children who were born with HIV who are now 25 years old and healthy (I2, I9). However, the same mentality exists. HIV is still associated with death. One informant mentions that the same mentality persists. People still view HIV as a death sentence. This creates a lot of fear among people:

> I think the fear of death is very strong. The fear that their children would get HIV was so strong that they would do everything possible to protect the normal children from HIV (I9).

It is obvious from this quote that HIV is used as a metaphor of death as Sontag (1989) writes in her book *AIDS and its metaphors*. In this quote the informant mentions fear as a powerful emotion that influences people's actions and behavior. From a theoretical perspective, the social construction of metaphors about HIV has a negative impact on the psychological well-being of people living with HIV. The society's behavior towards people living with HIV is negatively influenced as well (Sontag, 1989). One informant mentions one social and psychological consequence of HIV/AIDS being a metaphor. She explains that sometimes the perception of families of children affected by HIV hinders them from sending the children to school. Since they believe that their child will die soon anyway (I9).

Social class

Based on my interpretation, the HIV-metaphor of death is so strong that affected families have internalized this belief and does not send their children to school as a result. In fact, HIV metaphors influence the social identity of affected groups.

Some metaphors such as ‘social evil’ and ‘unethical people’ represent a negative belief about a person’s morality (Goffman, 1963). Nevertheless, social differences such as class influence how the public perceives HIV. This is only mentioned by one informant:

> If a child is born to a rich or educated family and unfortunately gets HIV, then maybe they would say that it’s because of bad influences from bad friends. But if the child is born to a poor family they would blame the parents for not educating him appropriately and not raising him appropriately. There is a difference. In school there is bias (I5).

In this quote I would like to focus my interpretation on the bias and different perceptions about rich and poor people. Wealth and poverty can also be understood as metaphors. Wealth has connotations such as ‘respected’, ‘educated’ and ‘successful’ which protect their social standing and social capital. According to Bourdieu (1986) education is a form of cultural capital. On the other hand, people living in poverty might be tied to metaphors such as ‘uneducated’ and ‘unethical’. HIV-metaphors are more damaging for poor people because their reputation and social standing are already vulnerable owing to their lack of social and economic capital. As a consequence, the social construction of HIV-metaphors intensifies inequalities and class distinctions (e.g. see Bourdieu, 1986; Sontag, 1989).

Power perspective

From a Foucauldian perspective, money is a metaphor for power as well. Because of rich people’s powerful position they are able to uphold their perceived morality. In a way, rich people are ‘morally impeccable’. Therefore, if a wealthy person is infected by HIV this can be viewed as ‘bad luck’ or ‘bad company’ instead of blaming the moral character of that person (e.g. see Foucault, 1977; Goffman, 1963).

One informant mentions the importance of education: “If you come from an uneducated family plus having HIV, you will be seriously looked down on” (I5). This quote is about cultural capital. Education is highly respected and appreciated in Asian cultures. In Vietnam, this culture is stronger in some provinces than others, such as Nghe An for instance. People affected by HIV hide their HIV-status in order to avoid being ‘looked down upon’ (I5). My interpretation of this phenomenon is the Asian notion of ‘saving face’. This means saving oneself from public humiliation. Also, saving one’s reputation in terms of cultural and social capital (e.g. see Bourdieu, 1986).

Moreover, appearance is mentioned by two informants (I5). One way of interpreting this is that appearance is tied to morality and social class. HIV is associated with ‘disfigurement’ and ‘scary’, ‘sick’ appearance. ‘Healthy’ and ‘beautiful’ people are regarded as ‘good people’ or having higher morality compared to ‘sick’ and ‘poor-looking’ people (Goffman, 1963; Sontag, 1989). A few participants argue that these metaphors limit condom use because people do not think beautiful and healthy-looking people can be HIV-positive (I5).

In brief, the history and culture of Vietnam as well as propaganda have created negative metaphors tied to HIV/AIDS. These metaphors question a person’s morality and thereby contribute to stigma. However, class, capital and power also influence individuals’ perceived morality. The consequences of stigma for children living with HIV will be presented in the following section.

6.1.2 Stigma and discrimination

There are several challenges for children living with HIV to access education. Yet, according to all informers, stigma is the biggest obstacle which hinders these children from going to school (I1-I9). Actually, all informants present a consistent view of the main problems children with HIV face in terms of education. Therefore, I could not find that many opposing views. Yet, a few interviewees

emphasize stigma while others emphasize the social disadvantages children with HIV face due to structural inequalities. Before starting the discussion about how stigma creates discriminatory processes, I would like to mention self-stigma. According to an interviewee, families of HIV positive children internalize public attitudes towards HIV and try to avoid stigma. This is explained below:

> The family of children living with HIV in some cases has self-stigma, they are afraid to be disclosed, afraid that people will know about their status. So they try to avoid interaction with people. Avoid sending their children to school (I9).

In this quote the informant claims that families are very scared of disclosure and the public's response to their HIV status. Therefore, they isolate themselves and avoid social interaction. From an empowerment perspective, self-stigma severely limits participation and emancipation (Adams, 2003). In turn, limited participation in the community results in limited social capital based on Bourdieu's (1986) perspective.

On the other hand, another participant mentioned that the fear of stigma might be worse than the actual stigma (I2). From Goffman's (1963) perspective, self-stigma has a significant impact on the child's psychosocial development. HIV-related stigma changes a person social identity and might cause low self-esteem, self-hatred and low self-confidence. Many factors discourage the children from attending schools. Also, the children learn from their caretakers to avoid other people because they pose a threat to others. An informant claims that this process increases their stigmatization because they act differently than other children (I5). In fact, self-stigma makes it difficult for NGOs or government agencies to offer support and services to affected groups because they want to hide their identity (I7).

Discrimination

Now I will focus on the discrimination children with HIV face in school owing to the fact that they are HIV-positive. First of all, the informers argue that the stigma

comes from the negative attitude and mind-set of teachers, principals, education managers and parents of other children in the same school (I2, I3, I5, I6, I8). Discrimination entails some sort of different treatment. Stigma might present itself through isolation, bullying or the child being forced to leave school. One interviewee explains this in the following quote:

> The consequences could be first, the kid would be isolated in school, so they would put the child in the last row in class. The teacher may say to other kids not to play with that kid. The teacher might take less care of the kid (I9).

In this quote the informant mentions different discriminatory actions done by teachers against children living with HIV. Teachers would physically isolate the child to the back of the classroom and socially isolate the child by telling other children not to play with that child. From Goffman's (1963) perspective, these children are isolated in school because their physical and moral character is viewed as a threat. A few informants mention that other children refuse to play with them (I1, I8). And that leaves a big scar in the heart of those children (I5).

However, discrimination involves both physical and social isolation. Based on my interpretation, other children might refuse to play with children affected by HIV based on the teachers' behavior and attitudes. Being ignored by teachers is a kind of emotional neglect and further limits the children's ability to learn. All informers state that there is no problem in children with HIV learning, playing or eating together with other children in school. There is no risk of HIV being transferred through normal contact according to the informers. A child has never been infected with HIV by another child in school (I2, I5, I6, I7). However, this kind of misunderstanding is common among teachers, principals and education managers (I5, I6). According to some informers, teachers often stigmatize children with HIV. Another example is made by one informant below:

> For example, if a teacher observes that a kid with HIV uses a cup to drink water, then of course it would be OK, but the teacher would not touch that cup to drink after that. But they would not tell anyone like 'this is

> disgusting' they would not say that. They would just silently keep themselves away from that cup (I5).

As in this quote, the teachers would not explicitly say something hurtful to the children with HIV, but they would show their attitude by their indifference. Similarly, if a mother in a neighbor saw her children play with children affected by HIV she would just tell her kids to come home (I5). From my point of view, it might be equally damaging to a child's psychosocial development to be ignored/excluded than to receive hurtful comments.

Stigmatizing beliefs

In fact, the teachers and service providers' age is said to be one reason for their stigmatizing beliefs, according to one interviewee. She explains that they studied at University a long time ago. At that time the education did not equip them with knowledge about vulnerable groups and how to respect diversity and difference. Therefore, she claims that it is difficult to try to change this kind of wrong understanding (I5, I6). Even the Minister of Education and Training has presented a similar attitude based on another informants quote:

> And I have met with the MOET minister and he himself even has the kind of wrong understanding of the infection mechanisms of these children. So he himself sympathize with the understanding that once the children affected by HIV/AIDS play together with another children and if they collide to each other or if they beat each other, then the possibility of infection is high (I6).

Based on my interpretation, this quote shows that the public fear of HIV is still strong. Such as this minister, people are still afraid that they cannot control the virus. They believe that there is a high risk of contamination through normal contact. Fear can limit the ability for rational thinking and understanding the scientific facts of HIV transmission. As a result, it becomes a serious problem when the highest levels of education managers and service providers have these

attitudes. This is a clear example of how misunderstanding of HIV transmission creates stigmatizing beliefs and discriminatory processes.

There is a lack of knowledge from local level to national level according to one informant (I3). On the other hand, another interviewee argues that there has been a significant improvement concerning discrimination in school from teachers:

> In recent years, with the new law on HIV/AIDS prevention this stigma and discrimination from the school has been improved, but still there is stigma and discrimination from the parents of other kids and from peers (I8).

In this quote, the informant claims that nowadays the biggest problem with stigma comes from other children's parents as well as peers. Other informants do not agree with this claim about the improvement mentioned in the quote above. Some argue that schools still stigmatize children with HIV. Teachers associate HIV with 'unethical' people. This is the main reason for them to ill-treat these children and not allow them to participate in school, according to one interviewee (I5). From an empowerment perspective, lack of participation is a huge problem in terms of ensuring equal access to education (Adams, 2003).

Morality

From Goffman's (1963) perspective this is a clear example of how HIV-stigma is linked to a person's moral character. As such, if teachers regard these children as 'bad kids', 'immoral' and 'unethical' they will treat them accordingly. Another informant gives an example of her own experience supporting families subjected to HIV-related stigma in pre-school:

> The baby was not even HIV positive but the parents were HIV positive. The baby was two years old. The caretakers don't touch the baby almost. So the baby would pee and things and they would not take care of the baby. They tried to limit the interaction, so that is one kind of consequence (I9).

Similarly, this quote also shows how stigmatization is about degradation of the parents' moral character (Goffman, 1963). In this example, a two year old child is neglected at daycare because of the parents HIV status. She represents a physical and moral threat. Regardless of the child's HIV status, caretakers are too afraid to care for the child such as changing diapers. They would not even touch the child.

From my understanding, this situation shows how just being associated with HIV in Vietnam brings significant consequences for children. Neglect influences the child's psychological development negatively. The discriminatory processes caused by HIV-related stigma places a heavy burden on families as well. As a result, families affected by HIV often hide their HIV status from schools (I1-I9). All interviewees mention: "The kid may have HIV but the school has no idea that they have HIV" (I9).

If the school does not know who is HIV positive or negative the families avoid being stigmatized and discriminated. However, if the family discloses their status or their child's HIV status, the child might be forced to leave school due to protests from other children's parents (I6, I9). Changing schools causes a lot of stress and financial constraints to an already marginalized population. In case the children must change schools many times they and their families might be discouraged and the child drops out from school (I8).

> A lot has changed. It is rare now that children living with HIV cannot go to school. It still happens because if you have to change school four times they will become discouraged and the children may not want to go to school anymore (I9).

In this quote, the informant states that there has been an improvement the last few years but children are still discriminated. Therefore, there is a huge gap between school enrollment and academic performance. In conclusion, HIV-related stigma causes a number of challenges for children to access education. Based on the informants' quotes, physical and social isolation, bullying, lack of friends and

unsupportive attitudes from teachers severely limit the children's ability to learn in school. Poor academic performance is therefore common for these children.

6.1.3 Social situation

In the following section I will analyze how the social situation of children affected by HIV/AIDS creates barriers for children's schooling. According to six interviewees, HIV positive children's access to education depends on their living situation such as family, social class, geographical location, ethnicity and social problems.

Poverty and high risk populations

First of all, the informants argue that there is a correlation between HIV, poverty and high risk populations (I1, I2, I4, I5, I6, I8). This is explained by an interviewee in the following quote:

> HIV prevalence is very high among injecting drug users and female sex workers in Vietnam and those are the very poor groups and for that reason their children will have difficulties accessing education (I8).

In the quote above, the informant explains that high risk groups are injecting drug users and female sex workers. Their children face difficulties in accessing education since the high risk groups often live in poverty. One way of interpreting this is that poverty makes people more vulnerable to social issues such as drug use and prostitution, mainly due to oppression and lack of opportunities (e.g. see Bourdieu, 1986; Foucault, 1977).

Two informants mention that there is a 'double burden' - the burden of poverty and drug addiction (I1, I5). HIV causes a third burden to an already struggling population. The main cause of HIV transmission in Vietnam is through needle sharing. In recent years, HIV has been spreading more through sexual contact because the majority of sex workers are also injecting drug users (I8).

Another interviewee argues that some drug users are so deep into their addiction so they have given up on life (I4). For these people, their children sometimes suffer abuse and/or lack of support. Family support is said to be an important factor in terms of education (I1). The correlation between HIV and poverty is mentioned below:

> The families of HIV people, the majority of them are poorer people. It costs to send kids to schools because of the tuition fee, because they also have to pay for books, all the other courses including extra-curricular activities. So that is very costly and sometimes they cannot afford it (I8).

According to the informant in the quote above, apart from social disadvantages experienced by people living in poverty they also struggle to pay tuition fees as well as other expenses. Consequently, based on my interpretation, poverty severely limits children's access to education and other social opportunities. In addition to poverty, there are other social inequalities such as geographical location, ethnicity and gender which influence HIV-positive children's access to education. One example is given by an informant below:

> There are a big proportion of ethnic minority children who are affected by HIV/AIDS, especially those who are living in the northern mountainous areas in Vietnam. For example, children affected by HIV/AIDS might be having a disability, they may be living in the ethnic minority areas, they might be a girl. Then they might be more and more difficulties compared with those who are living in the big cities, who is a boy and who is living in a better off family (I6).

Culture and gender

This quote is subject to many interpretations. Firstly, this quote is about gender inequality. The informant states, if a child affected by HIV is 'a girl' she might face 'more difficulties' compared with 'a boy'. From a cultural perspective, HIV is especially stigmatizing for girls. In Vietnam, there is a male preference even though it is not as prominent as other Asian countries. Nevertheless, because of the male preference more expectations are placed on girls to be 'obedient',

‘compliant’, ‘innocent’, ‘loyal’ and ‘hard-working’. As a consequence, girls and women who live with HIV face a higher level of social rejection because they are unable to meet these gendered expectations (e.g. see Bourdieu, 1986; Sontag, 1989).

Then again, I am aware of the influence of my Swedish perspective. Besides, the Vietnamese society has somewhat moved away from such traditional practices even though the same expectations of women still exist. From a power perspective, men have a higher social rank than women. Men’s perceived morality and reputation is therefore not as vulnerable in comparison to that of women. For example, promiscuity in young men can be overlooked while ‘promiscuous’ women would be viewed as ‘immoral’ and threaten the family’s reputation (e.g. see Focault, 1977; Goffman, 1963).

Ethnicity

Secondly, another way of understanding this quote is to analyze inequalities based on ethnicity. In the quote above the informant mentions that there is a high HIV prevalence among ethnic minority children. She also states that people who live in the northern mountainous areas of Vietnam are particularly affected (I6).

From a theoretical perspective, ethnic minority children face high levels of oppression, both social and physical exclusion. Since ethnic minorities often live in disadvantaged remote areas and therefore face challenges in accessing basic services such as healthcare and education (e.g. see Foucault, 1977). For example, one informant mentions that some ethnic minorities who live in northern mountainous areas have to travel about 100-200 km to the nearest healthcare facility (I8). In addition, ethnic minorities often live in provinces which border to China, Laos or Cambodia. Drug smuggling, trafficking and prostitution are common problems in border provinces. Because of the amount of drugs there is a high prevalence of HIV in these areas (I5, I6).

Family

Moreover, access to education for children affected by HIV is influenced by their family situation. For example, if the child's parents are still alive they have a much better chance of being healthy and attending school according to two informants (I2, I9). In some cases the children live with their grandparents or extended family if their parents have passed away. Yet, many children live in institutions such as social centers (I9). The interviewee explains in the following quote how the child's living situation influences education:

> The children in the social centers, in most cases, have difficulty to access education in mainstream schools. In many centers I have talked to people, it is almost impossible for the children from the centers to go to local school. It's very, very difficult (I9).

As stated in the quote above, it is very difficult for institutionalized children living with HIV to access public schools. Instead, the social centers organize education inside the center which does not have the same quality as public schools, according to one informant. Because the child is taken out from the community and put in a center they are already physically isolated and they are not socially integrated into the community (I9). In light of Bourdieu's (1986) work, these children's social and cultural capital is extremely low. As such, the children have no social network because they are excluded from their community and therefore lack social and cultural capital. This makes the children vulnerable to many things.

Health

Lastly, another challenge for HIV positive children is their physical health. Some children with HIV have special needs in terms of education; this is mentioned by one informant. Even though antiretroviral therapy is free, it requires a strict routine and a healthy diet (I9). This is a problem for poor families as well as

social centers. Many are able to stay healthy thanks to treatment but some children suffer from opportunistic infections.

HIV can also affect the brain, causing mental problems. Besides, the informant also mentions that schools in Vietnam are not equipped to take care of children with special needs (I9). In addition, another interviewee mentions that there are 50 pupils in each class and from a young age there is a heavy workload in Vietnamese schools (I2). Based on my interpretation, there is limited understanding that children with special needs have the right to learn and benefits from education. In fact, children with visible disabilities are not even given a chance to go to school (I6). The schools in Vietnam are not prepared to pay extra attention to children with special needs mainly due to lack of teachers, resources and understanding. As a result, education in Vietnam is far from inclusive which cause problems for vulnerable children.

In sum, the social situation of children living with HIV is essential in terms of access to education. The majority of children affected by HIV/AIDS come from socially excluded groups and they are therefore highly vulnerable. Poverty and social inequalities are major barriers for these children to perform well in school. After analyzing social and cultural barriers I now turn to strategies to overcome these issues. This is presented in the following section.

6.2 PART 2: Strategies

6.2.1 Treatment

Now I focus my attention on analyzing different strategies to overcome challenges children face in accessing education. All of the participants' work reflects an understanding of the concept of stigma. The interviewees present similar perceptions about the main problems children living with HIV face in accessing education. However, in terms of strategies I found much more variety in

responses. Firstly, one participant mentions the availability of antiretroviral therapy as the greatest opportunity for children living with HIV in Vietnam:

> I think the biggest opportunity that I have seen is the availability of treatment for children. Now the children with HIV get immediate treatment (I9).

Nowadays, pregnant mothers who are HIV positive are entered into a healthcare program. This program aims at limiting the risk of mother-to-child transmission by providing mothers with information and treatment. Early diagnosis of the baby makes it easier to provide early interventions according to the informant. The mortality of people living with HIV is much lower now than before. Therefore, less children living with HIV lose their parents (I9).

In 2015, 4596 children below 15 years old receive ARV treatment in Vietnam according to another informant who works within a government agency (I8). Most informers state that ARV treatment is free and available in Vietnam. However, one interviewee who works for an NGO disagrees:

> Some commune in An Giang province near Cambodia border, lack medicine for children. They use ARV for adults and they cut three parts or two parts for children, very dangerous (I3).

Based on my interpretation, this informant means that because of lack of medicine the children take a smaller dose of adult ARV which is not meant to be used by children. I believe the lack of medicine has two reasons. Firstly, access to healthcare is limited within border provinces. Secondly, the number of unreported children living with HIV is high. If children are not tested for HIV and reported they cannot receive free treatment:

> That is a problem in Vietnam. The number of children a bit more than 4000, but in fact maybe 20 000, we don't know. I think it's three times higher than reported numbers. I think it's three times higher than that in Hanoi, because Hanoi is nearly 7-8 million people. Why only 40-41 children affected by HIV/AIDS? Cannot believe! (I3).

In the quote above, the informant is critical against the number of reported children with HIV in relation to the population rates. He argues that the real numbers are in fact three times higher than reported cases. As presented above, the informants who work for NGOs are more critical than those who work within governmental agencies. From a power perspective, this variation in opinions could stem from different power positions. Government officials usually have more power and higher status than NGO staff. Nevertheless, NGO staff might have closer contact to affected groups and therefore might be able to view things more critically. It might also have to do with their representation. Government officials might feel obligated to present achievements since they represent the Vietnamese government. NGOs might to a larger extent represent the people instead of a state authority (e.g. see Foucault, 1977).

HIV/AIDS Funding

Furthermore, the informants state that in Vietnam about 70 percent of HIV/AIDS funding is from international donors and the rest from the national budget (I1, I4, I8). Yet, from 2017 there is no new commitment from international donors because Vietnam has reached a low-middle income country and the dependency on official development assistance is facing out (I1, I2). Most informants are optimistic that treatment will remain free. Especially one government official, he argues that later on when funding is reduced health insurance will provide full coverage for ARV treatment:

> The government understands that the consequences of lack of funding will be huge in terms of social and economic development. And that has been evidenced by African countries, when the funding for HIV/AIDS prevention has been reduced in those countries the GDP suffered. For that reason, our Prime Minister promulgated a decision to request for securing enough funding for HIV/AIDS efforts in Vietnam (I8).

This quote presents a high level of understanding of the consequences of reduced funding and how important it is for the government to secure enough funding for HIV/AIDS prevention. Nevertheless, another government official hopes that ARV will at least be cofounded by the government. According to her, this is only fair because treatment is not free in case of other chronic deceases (I4). Based on her statement, stigma surrounding HIV/AIDS might have attracted more funding than other deceases (e.g. see Goffman, 1963).

Despite the fact that ARV will probably remain free, funding for other kinds of HIV programs might be reduced based on my interpretation. For example all efforts in promoting education for children living with HIV might suffer. The government's capacity to allocate resources for children is criticized by one informant who works for an NGO. He argues that in Hanoi money is used to build high buildings and not prioritized for children (I3).

Based on my interpretation, economic growth creates higher levels of social inequalities. From a power perspective, the state and wealthy people does not invest in excluded groups. This is a way for the government to use stigma to maintain the social order and social hierarchy. It is more profitable for the government to invest in the middle and upper classes instead of 'wasting money' on the social out-cast. As previously mentioned, children with HIV belong to the lowest class. They are most often the children of drug users and sex workers. Since these social problems are viewed as 'social evil' it influences the government's willingness to support this target group (e.g. see Goffman, 1963; Foucault, 1977).

Corruption

Additionally, based on my analysis corruption is a major problem in Vietnam. However, this is not explicitly stated by any informant. Perhaps corruption is too sensitive to mention in a one-party state such as Vietnam. Yet, most informants state that funding is a big problem. When I read between the lines some statements are linked to corruption. For example, one informant states that the

government ministries have 'poor coordination' (I6). Another informant who works for an NGO states:

> We in Vietnam have a big problem about that. There is a big gap between theory and activities. They say like this but they do like that (I3).

I interpret this statement as an overall lack of trust in the state. Since the interviewee states that the government does not deliver what they promise. The lack of transparency and accountability will become an even larger problem when international funds decline. Nowadays, there is foreign monitoring of official development assistance. Later on the lack of foreign monitoring will threaten fair allocation of resources. Corruption hinders fair distribution of resources and social opportunities. This further marginalizes already excluded groups and limits access to education for children affected by HIV (e.g. see Bourdieu, 1986; Foucault, 1977).

6.2.2 Governmental support

The informants mention a number of strategies the government applies in order to ensure access to education for children living with HIV. Firstly, there is an anti-discriminatory HIV law in Vietnam. The government regards children infected and affected by HIV as one group of children in disadvantaged circumstance (I9). There are sixteen circumstances for children in special needs. The children who are in that list get welfare from the government. Welfare includes monthly allowance and health insurance (I7, I8). Most importantly the government recognizes their vulnerability. The law clearly states that all children have the right to education regardless of HIV status. This is mentioned in the following quote:

> And another opportunity is the law. It's a law that prohibits stigma and discrimination, reaffirms all the rights for people living with HIV including children living with HIV (I9).

The informant explains that the law is a clear message from the government that any form of discrimination or stigma is against the law. Children are thereby legally protected. In order to implement this law the government has developed an action plan. This is mentioned by several informants (I3, I7, I8). One example is presented below:

> Vietnam's policy is that all children affected by HIV/AIDS have the right to go to school. And the goal of the national action plan is from 2016-2020 highlight that 80-90 percent of children with HIV/AIDS must attend school (I3).

In the statement above, the government emphasizes equal right to education and has set the goal of 80-90 percent school enrollment of children affected by HIV. In order to follow this action plan the government performs many activities. One informant from the Ministry of Education and Training, explain that they promote inclusive education by providing annual documents, seminars and community-based training. They also educate fellow government staff about equal access to education for children living with HIV (I4).

Another interviewee from another government agency mentions that they have many activities to enhance children's access to education (I8). Firstly, they developed a TV program which is called *Human arms* for children with HIV. The program had successful results in some cases but stigma and discrimination is still a common problem according to this government employee.

Furthermore, he mentions that they promulgate legal document to the national assembly and promote policies which enable people living with HIV to receive loans from the bank. Also, they developed methadone institutions for drug rehabilitation, health insurance for poor people and community-based models. Such models provide mobile testing of HIV and dispersal of HIV drugs at the commune level to enhance access to healthcare for rural communities (I8).

There is also collaboration between MOET, UNICEF and local NGOs to perform monitoring and evaluation of the national action plan. Representatives travel to

different provinces to evaluate how many of the registered children living with HIV attend school. However, because of many unreported children living with HIV it is difficult to gather valid data according to one interviewee (I3). Apart from these strategies, the Department of HIV/AIDS Prevention enforces the law with sanctions:

> We also promulgate drafts of legal documents and administer fines and penalties against behavior of violations of enfranchisement. For example, in the educational sector, the schools or educational institutions who refuse children to their school or kick them out of the school because they are positive of HIV. First of all the school will have to get the children back and will have to pay some fine from 5 million to 10 million VND or even higher penalties depending on the severity of the violations (I8).

Since stigma and discrimination is prohibited within the educational sectors, schools are sanctioned if they mistreat children affected by HIV according to the quote above. Based on my interpretation, the government provides various efforts and activities to ensure equal access to education for children living with HIV. Yet, progress takes time because stigma is the number one barrier for children with HIV to access education. One government official mentions the improvements:

> Thanks to all of these efforts the percentage of children with full access to services has increased significantly. Maybe only about 30-40 percent of them had access but now about 70-80 percent (I7).

In this quote, the interviewee states that school enrollment has increased significantly. However, based on my interpretation stigma and discrimination still has a negative impact on education even though school enrollments has increased. The government officials do not provide data concerning academic achievements. For example, data on how many children with HIV who pass primary school or secondary school is not available. These numbers would be more valuable. One informant who works for an NGO argues that there are many unreported children

with HIV since the families do not disclose. As a result, the government's data is inaccurate (I3).

Yet, most informants acknowledge that there have been improvements (I1, I2, I4, I6, I8, I9). However, some informants who work within NGOs argue that the HIV law is not rigorously and systematically enforced by the government (I9, I5). Instead, community-based organizations and non-governmental organizations support children who have been forced to leave school due to their HIV status. They visit the schools and inform teachers and principals of their legal obligation (I5, I6).

Inequality and social class

Based on my interpretation, social problems such as inequalities hinder the government to implement laws effectively. Education is not free in Vietnam. Both private and public schools are profit-driven and most families pay extra for good grades according to one interviewee (I6). Parents of other children sometimes threaten to change schools if the HIV-positive children do not leave. This issue is mentioned by most informants (I2, I4, I5, I6, I8). One example is presented by an informant below:

> Then I think the mentality of the school and the teachers 'why do I have to trade one HIV positive kid for 100 or 1000 normal, healthy and wealthy kids'. Children living with HIV are usually sick and poor so if they are not sick they are mostly poor. Does the family of children living with HIV, influence enough to move the government officers to act? (I9).

This quote is about class differences. The informant claims that schools are profit-driven and questions the power of these families. Therefore, I would like to highlight class fractions and class distinctions which are prominent in the education system. A strong legal framework recognizes all children's right to education. In spite of this, the government fails to implement the law effectively due to class fractions in a corrupt system. These families have minimal power

because of their low social standing and limited economic capital (e.g. see Bourdieu, 1986; Foucault, 1977).

In terms of inequality, the government has several strategies to support people who are living in poverty. This is relevant because most children living with HIV are from poor families. According to two government officials, the government provides monthly allowances, health insurance, nutritional support and institutional care for orphan children (I7, I8).

Yet, at the practical level a lot of resources are needed to meet children's needs. An informant argues that the financial support the children receive does not cover all costs. The monthly allowance is equivalent to 136 SEK per month which people cannot survive on according to the informant (I9). Therefore, many families are forced to abandon these children and leave them to orphanages. The children's physical needs are met within social centers but their access to education is limited as discussed earlier (I7). This is mentioned by the informant below:

> The government accepts children living with HIV into the orphanage, into the social protection centers if nobody takes care of them. So in those social protection centers they would be having accommodation and food but access to education is another story (I9).

Based on this quote, access to education for orphans is very difficult in Vietnam. Their HIV-status makes it even worse and severely limits their social opportunities. If the monthly allowances were higher perhaps parents or other caretakers would afford to keep their children within the community. Based on Bourdieu's (1986) work, social integration within the community enhance children's cultural and social capital and thereby access to education.

In brief, the government provides countless of different projects and strategies to promote access to education for children affected by HIV/AIDS. Yet, there are a number of social and cultural barriers such as corruption and inequalities which

hinder their policies to be successfully implemented. The following section is about confidentiality.

6.2.3 Confidentiality

Most informants mention confidentiality as an important strategy to protect the privacy of children living with HIV. According to the law the HIV status has to be protected and have to be made confidential. Due to confidentiality the schools do not know if the children are HIV positive or not (I1, I2, I3, I5, I6, I7). It is also against the law to require HIV-tests of children in school. Several informants claim that confidentiality is a way to prevent stigma and discrimination (I1, I3). For example, if people do not know the children are affected by HIV they will receive normal treatment (I9). Similarly, another interviewee states that many children affected by HIV/AIDS are still in school thanks to confidentiality (I6).

Confidentiality is an important way to protect the privacy of children affected by HIV. Yet, confidentiality will not reduce stigma, only prevent stigmatization. One informant states that in some cases the teachers know about the children's HIV status but keep this information confidential from other children's parents (I2). According to another interviewee, the teachers disclose the children's HIV status in front of the class or inform all the parents of other children in school in order to encourage others to support them. However, this action unintentionally makes stigma and discrimination worse (I5). Likewise, two informers explain that some health staff at the commune level does not keep confidentiality or they leak the information about who is living with HIV/AIDS in that area. 'Stigma gossip' is said to hinder the protection of confidentiality (I1, I3).

On the other hand, confidentiality causes problems according to few informants. Firstly, it becomes difficult to reach out to people living with HIV because their personal information is kept secret (I7). Secondly, there is some conflict between teachers and health staff concerning confidentiality. The teachers are unable to

offer HIV-positive children extra support because of confidentiality (I3). Lastly, disclosure could be something positive. Two informants argue that people living with HIV are able to feel more comfortable if they disclose about their HIV status since fear of stigma could sometimes be worse than actual stigma. Besides, if people disclose they are able to live without secrets and may receive support from their family (I1, I5).

Confidentiality varies in reference to geographical location. In rural communities it is more difficult to keep families HIV status confidential. Also, in rural communities there might be limited possibilities for children to change schools due to stigma in comparison to big cities. For instance, one informant explains that neighbors might work at the local healthcare center and there is more gossip. In contrast, it is easier to protect confidentiality in big cities like Ho Chi Minh City with 10 million inhabitants (I9). In sum, there are both positive and negative aspects of confidentiality.

6.2.4 Raising awareness

All informants claim that education and raising awareness is the most important strategy to reduce stigma and ultimately increase access to education for children living with HIV.

Lack of knowledge

Everyone I interviewed mention that there is no risk of HIV transmission through casual contact and that the public needs to be educated about this in order to reduce fear and stigma concerning HIV/AIDS (I1-I9). One informant gives an example below:

> Many people think that HIV can be transmitted through the other contacts, the everyday contact; the lack of knowledge about the roots of transmission is the main cause for stigma and discrimination. They fear the

> normal contact like shacking hands or hugging, even some people think that mosquito bites can transfer HIV (I1).

This quote is about the lack of knowledge and awareness concerning HIV/AIDS. Based on my interpretation, the level of awareness of the public and government agencies has previously been low and sometimes still is. As mentioned earlier, top educational managers has presented a kind of wrong understanding of the risk HIV children pose by attending school (I6).

Segregation

Another government official explains that her agency educates the public by sending fact sheets to schools about HIV transmission and provides training of government staff. In some cases the lack of knowledge and fear concerning HIV transmission has led some schools to create a separate class for children affected by HIV, according to some interviewees (I3, I7). One informant gives an example:

> In Ba Vi they have a separate center only for children positive with HIV […] They don't allow those children to go to school and study with other children, but after I went there together with some other person from the ministry of health and communist party and some other from Hanoi, they agree to bring all the children to the school but in a separate class only for children positive with HIV (I3).

This quote is about segregation of children affected by HIV. From my understanding, the government collaborates together with the communist party and local NGOs in order to advocate the right to education for all children. The quote above is a clear example of how strong HIV-related stigma is. From a power perspective, these representatives from the government and the communist party have high social standing and powerful positions. Regardless, the fear of HIV is stronger than their influence to change people's minds. The principal of the school refused to fully integrate HIV positive children within the school.

Therefore, a separate ‘HIV-class’ was created in order to avoid violating the right to education for children living with HIV (I3).

Based on my interpretation, this kind of segregation is not in anyone’s favor. The children affected by HIV might feel like ‘bad kids’ and their social identity will be damaged. Also, the other children in school will learn that children with HIV are ‘dangerous’ and not allowed to be around healthy children (e.g. see Foucault, 1977; Goffman, 1963). Another government official, states that the government tries to make sure that children have full access to their rights by promoting inclusive education instead of isolating children in special classes (I7).

Contact with affected groups

Moreover, there are different strategies to educate the public. One participant states that information and contact with affected groups is the most effective way to reduce stigma:

> When fear is reduced stigma is reduced, but also to create solidarity and empathy to other people. They can interact with people living with HIV so that they will reduce stigma (I9).

This quote is about fear of the unknown. The informant claims that contact with affected groups would reduce fear and stigma. If people affected by HIV interact with the society it would enhance empathy and solidarity. When HIV is seen in metaphors such as ‘death’ or a ‘ghost’, fear is natural. From a theoretical perspective, HIV represents a physical fear as well as a moral fear of being infected with ‘social evil’. Therefore, interaction prevents stigmatization and dehumanization. Interaction also challenges deeply rooted metaphors as well (e.g. see Goffman, 1963; Sontag, 1989).

Communication

The government and a number of NGOs in Vietnam organize communication activities to enhance awareness and understanding. One government official states

that the awareness of the public as well as government agencies has been improved (I8). Additionally, some informants explain how they communicate directly with the schools in order to raise awareness. Besides, all schools need to admit children living with HIV in order to reach normalization. There is a need for top-down implementation of the policy and law by the government, according to one informant (I7). Similarly, another informant gives the following statement:

> I think integrating them in schools with other kids is something that we should do. But for children affected by HIV to be mingling with other kids, I think we need some kind of long-term top down sustained intervention (I5).

In this quote, the informant argues that the there is a need for long-term interventions implemented by the government in order to achieve integration. On the other hand, some informants argue that most strategies to educate the public have failed because the education is boring. In order to reach a sustainable intervention education must be interactive, fun and engage with affected groups (I8). According to one informant children need to be educated from an early age to prevent and reduce stigma. Early education and early provision of knowledge is essential with the aim of changing the mind-set of future generations. Living evidence is more powerful in changing people's minds (I5). Some informers argue that movies and documentaries are more effective than just lecturing about HIV. An informer gives an example below:

> We developed a talk show and we showed that on TV about the rights to education for children. We also launched a documentary film shown on Nghe An provincial television about children's rights to access education. Number three; we launched a communications campaign in ten schools in the area where we see stigma and discrimination. So after the three activities we received very active support from the government. And there is significant improvements in Nghe An when it comes to stigma and discrimination thanks to the activities (I5).

In this quote, the informant gives an example of interactive and successful strategies which reduce stigma and discrimination. I interpret, 'active support from the government' as collaboration between NGOs and the government as necessary for successful implementation. On the other hand, one informant argues that stigma and discrimination cannot be prevented only reduced (I4). Based on my understanding, some people will keep their mind-set regardless of education because HIV-metaphors are so deeply rooted within the public perception. In recent years, there are still some posters about the dangers of HIV with an emphasis on 'death' and 'social evil'. In my opinion, the influence of the war time is strongly related to stigma. From a historic perspective, thousands of years of war in Vietnam have created a strong survival instinct which in turn makes the society harsh and exclusive to deviance (e.g. see Bourdieu, 1986; Goffman, 1963; Sontag, 1989). The informant below gives an example of persistent attitudes:

> So when we conducted that campaign we can see that there has been some change in the mind-set but we have also faced the fact that even though they understand that ok this is the life of the children with HIV, but at least three principals from the schools were still very indifferent and didn't care. And they still kept their mind-set that: I cannot control if the kids are in my environment. So we think that the mind-set and the attitudes of the teachers are very important (I5).

In this quote, the informant argues that it takes time to change public attitudes and that some people will never change their mind-set. Several informants agree that it will take time to reach a long-term change (I3, I8). Nevertheless, nowadays many children living with HIV have access to education thanks to confidentiality.

In brief, the informers give some examples of awareness raising strategies such as providing scientific evidence, advocacy and information about HIV, delivering fact sheets to schools, training teachers and government staff, distributing DVDs, providing TV talk shows and documentaries and conducting seminars, workshops and projects in high stigma areas (I1-I9). Based on my interpretation, change takes time but the efforts done by practitioners will eventually move towards a more

inclusive society and reduce stigma and discrimination concerning HIV in Vietnam.

6.2.5 Empowerment

I will now focus on empowerment which is a central theme throughout the interviews. Informants mention that promoting equal rights to education through empowerment could entail different things. For instance, informing people about their rights and standing up for them in school (I5, I6, I7, I8). One interviewee who works for a non-governmental organization describes her collaboration with CBOs:

> We work with the community-based organizations through empowerment. We work with organizations for people who live with HIV, sex workers or drug users and empower them so that they can protect their children […] we provide different kind of support for those children, could be nutrition support or scholarships (I9).

In this quote, the informant describes empowerment as offering different kinds of support in order to enable children to access school. From an empowerment perspective, the organization supports vulnerable families. Children of prisoners, drug users, sex workers, orphan children and children affected by HIV are the most vulnerable children. Based on my interpretation, these strategies enable families to keep their children at home instead of being forced to leave them at social institutions (e.g. see Adams, 2003).

Community-based approach

Apart from scholarships, the informant states that the organization supports children by finding a big brother or big sister to help them with home-work (I9). One informant suggests top-down interventions (I5) while others mention the need for full-time social workers at the grass-root level (I2, I3, I4, I7, I8). Several informants emphasize the community and advocate for a community-based

model/approach. The first challenge is community awareness. The awareness within the community is still very limited, according to one informant (I7). The community is mentioned by another informant as well:

> Now I think the children can attend school like other children and some children can study very well. And now have the support from the law but they didn't receive any support from the community. I mean that the law is a supportive factor but the community is not a supportive factor. I think the resources in the community are very big and if we can encourage and raise their awareness about this they can give a lot of support for children (I2).

In this quote the informant suggests that the community should be transformed into a supporting factor instead of stigmatizing and excluding children living with HIV. Based on my interpretation, community-based approaches increase access to healthcare and education. These empowering strategies aim at using existing resources within the community and thereby increase integration and participation of these children. As mentioned earlier, the community is an important factor for the social life and well-being of children. The community is also important in terms of social and cultural capital of families (e.g. see Adams, 2003; Bourdieu, 1986).

Rights-based approach

In contrast, other informants favor the right-based approach in supporting children's access to education. According to one informant they had to communicate directly with parents at schools, to let them know that children themselves need to be assured their human rights (I7). Some parents forget that children with HIV are also human and needs to have their human rights protected. Similarly, another interviewee who works for a NGO explains how she educates teachers about humanity and fundamental human rights:

> So our approach is child-rights based; the right of survival, participation, schooling and the right to privacy. Only when we start to have a right-

> based approach can they start to think about it in a fairer way and allow the kids to participate (I5).

This quote is about protecting children's human rights. From an empowerment perspective, I would like to highlight participation. Even if children are enrolled in school, stigma and discrimination dehumanizes them and thereby hinder them from participating in school. Teachers need to be educated about the roots of transmission to reduce fear and about humanity in order to treat these children with dignity and kindness. Yet, participation is the key for integration and reducing stigma (e.g. see Adams, 2003).

Emotional support

Another informant states that her NGO empowers oppressed groups, especially if parents do not send their children to school because they believe they are going to die. Emotional support through counselling can give families hope for the future. Below she gives an example of the hopelessness some people experience:

> One mother who is HIV positive and working as a sex worker, and the kid had no father. So the mother works at night. So if the kid goes to school the mother has to wake up early in the morning to bring the kid to school. So the mother was like: I have to wake up early and she is going to die anyway (I9).

In this quote the mother is a heavy drug user and sells her body to survive with her child. As mentioned earlier, education is not free in Vietnam and it would cost the mother a lot of money if she had to be awake all night as well as during daytime. In regards to the cultural context, the mother might be subjected to stigma in the school for many different reasons.

Firstly, she is a single mother, which is still looked down upon in a traditional society like Vietnam. Secondly, she engages in 'immoral behavior' such as drug use, sex work and lives in poverty. Lastly, both of them are HIV positive.

Therefore, the mother lacks economic, social and cultural capital which hinders her daughter from accessing school (e.g. see Bourdieu, 1986: Goffman, 1963). An informant gives an example of her perspective:

> The multidimensional way or the intersectional approach or lens is important nowadays. It is about changing society. It is about changing the system that is better and more inclusive for those children affected by HIV/AIDS […] so moving away from the charity-based, moving away from the medical-based. It is more about the rights-based approach (I6).

This quote is about intersectionality, that stigma is a multidimensional issue. Instead of focusing only on charity or ARV treatment for children with HIV, she argues that the right-based approach entails equal rights for all children. There is a need for a holistic perspective in order to overcome stigma. Based on my interpretation, people living below the poverty line are more vulnerable and might not have the means to protect themselves with condoms. In fact, condoms are very expensive in Vietnam. Drug use and sex work is associated with poverty as well. That is another reason why poor communities have a higher HIV prevalence. As a result, HIV-related stigma is not a single process since it reinforces poverty and structural inequalities such as age, class, gender, ethnicity, sexuality and geographical region (e.g. see Foucault, 1977; Goffman, 1963).

Self-help groups

Additionally, most informants mention other empowerment approaches such as self-help groups, peer-support and counselling (I1, I5, I6, I7, I8, I9). Several informants mention that self-help groups are important strategies for people affected by HIV to share experiences and offer mutual support. A government employee explains that self-help groups empower people to join activates. This makes them more courageous in facing their situation and also more willing to participating in the preventive and treatment services for HIV (I8). Another

informant who works for a NGO explains how they work to empower people and reduce self-stigma:

> First one is self-stigma. We need to provide education for people living with HIV/AIDS including children with HIV, to love themselves, to have self-esteem and to be self-confident. And we need to be brave enough to raise our voice when we see or observe stigma or discrimination. And also we need to teach these people to raise their voice when they see stigma and discrimination because it is their self-confidence that will be exemplary for others to learn from […] For people with HIV themselves we have a series with life-skills training activities educating them about self-esteem, self-love, public speaking skills, leadership skills and project management skills (I5).

In this quote, the informant gives an example of a strategy which is aimed at the children adapting and coping with stigma. The organization uses empowerment to reduce shame and promote self-love. This method empowers people to stand up against discrimination and participate in society. Based on my interpretation, it is important to offer counselling to people affected by HIV. Stigma reducing interventions must also involve affected groups in order to normalize HIV in society and prevent affected groups from isolating themselves (e.g. see Adams, 2003).

Another informant mentions how self-help groups can promote a positive image of HIV-positive people (I1). Based on my interpretation, HIV-stigma cannot be reduced if people hide their HIV status. Yet, based on the current situation one cannot blame people from hiding their status in order to access healthcare and education. However, with the purpose of raising awareness and empowering affected groups it would be effective if more people would step forward and disclose their HIV status. This would normalize HIV in society and educate the public that anyone can be infected with HIV.

In turn, this would also reduce the spread of HIV since stigma is the main obstacles in preventing spread, according to most informants (I1, I2, I5, I6, I7, I8, I9). By presenting a positive image of people with HIV the public would move away from past misconceptions and metaphors that only 'bad', 'unethical' or 'poor' people who engage in 'social evil' are able to get HIV (e.g. see Goffman, 1963; Sontag, 1986). A similar example is made by another informant below:

> When they start to interact with the government agencies those agencies start to look at them in a different way because in the past they have said that these are uneducated and unknowledgeable people. So they tend to look down on them but now they say that wow they do have knowledge. So when they interact with different agencies and present different activities conducted by a self-help group, the agency would say that they are very persuasive, very clear in their presentation and that helps reduce stigma and discrimination. Because they see that these are professional people (I5).

In this example, an awareness campaign was led by a self-help group. After the campaign the government officials' mind-set has changed. Instead of looking down on people with HIV as 'uneducated' they now see them as capable and professional people. These kinds of client-led and participatory approaches are especially effective in changing people's attitudes. These approaches humanize HIV and show that HIV has nothing to do with a person's abilities or morality (e.g. see Adams, 2003; Goffman, 1963).

In sum, empowerment entails stigma reducing interventions such as a community-based approach, rights-based approach, emotional support, self-help groups and participatory led awareness campaigns. All of these strategies promote equal rights to education for children affected by HIV/AIDS.

6.3 My results in relation to previous research

Metaphors and stigma

Based on my results, stigma is the greatest challenge for children living with HIV to access education. Stigma creates discriminatory processes which negatively influences education for these children in many different ways. Stigma is caused by the public's stereotyped beliefs about people affected by HIV/AIDS. HIV is used as a metaphor with many different social meanings. As such, HIV is associated with death, drug use and sex work. This corresponds well with the research by De Schacht et al. (2014) and Sontag (1989) who claims that HIV is regarded as a death sentence. My results suggest that HIV is particularly associated with 'social evil' or 'moral evil' which confirms Goffman's (1963) theory of stigma which is about degradation of a person's moral character.

Children living with HIV are viewed as 'unethical', 'bad' kids who come from 'bad' families. On the contrary, Boggiano et al (2014) mention that some people judge the morality of children based on how they acquired HIV. For example, if they were born with HIV they are less stigmatized. Instead, informants within my research claim that children are stigmatized regardless of how they got HIV. This is in line with Baxen and Haipnge (2015).

Discrimination

Stigmatizing attitudes create discriminatory behavior from teachers, principals, education managers, peers and parents of other children. These studies reach similar conclusions (Baxen and Haipinge, 2015; Rawson, 2012; Starevic and Begavac, 2005). Discrimination strictly limits the children's ability to participate in school because they are at times forced to sit in the back of the classroom and are not allowed to play or eat with other children. Sometimes, children with HIV are forced to leave school due to parental protest. Therefore, stigmatization results in social isolation, exclusion and humiliation. This corresponds well with Boggiano et al. (2014) and Nguyen et al. (2012). Yet, it is important to mention

that not all parents in Vietnam have stigmatizing attitudes about children with HIV. According to Boggiano et al. (2014), only 25 percent of parents of other children oppose integration of HIV-positive children into public schools. The rest of the parents present positive views of integration.

Social and cultural barriers

Even though stigma is the greatest barrier children with HIV face in accessing education, there are other social and cultural barriers which severely limit access to education for these children. Such barriers are for example, poverty, corruption and inequalities in ethnicity, class, gender, geographical location and orphan-status. Children affected by HIV in Vietnam are most often from poor families, ethnic minorities or their parents engage in drug use or sex work. These findings are supported by White (2014), who claims that gender, poverty and inequalities influence access to education. Ethnic minority children and children living in poverty in Vietnam show persistent lower school performance, according to the World Bank (2016). Besides, the majority of out-of-school children are girls (Colclough, 2014).

Families affected by HIV lack economic, social and cultural capital which hinders their children from accessing school. Besides, some children are orphans and live in social institutions. Consequently, HIV-related stigma reinforces structural inequalities and reproduces oppression which further marginalizes an already excluded group. Similar conclusions are drawn by Abadia-Barrero and Castro (2006), who argue that poor children are excluded from education because stigma intensifies inequalities. However, the same authors claim that the 'AIDS-orphan' label brings social advantages which are inaccessible for poor children. Such findings are not found in this study, although one informant mentions that HIV treatment is free while treatment for other chronic deceases is not. Thus, there is some positive discrimination for people living with HIV/AIDS as well.

Confidentiality

The informants mention extensive strategies in order to ensure equal rights to education. Firstly, the most surprising findings are the conflicting results about confidentiality. The informants agree that there have been significant improvements in recent years and many children living with HIV are attending school nowadays. However, these children are able to go to school thanks to Vietnam's confidentiality laws which makes it possible to hide their HIV-status. The only way to ensure the right to education for children affected by HIV is to keep their diagnosis secret. This corresponds to earlier research which claims that disclosure actually creates stigma (Boggiano et al., 2014).

On the other hand, HIV-related stigma is still a major problem which is not reduced by confidentiality. Besides, confidentiality makes it difficult for practitioners to reach out to vulnerable groups based on my findings. Moving forward, informants claim that they promote disclosure with the aim of reducing stigma in a long-term perspective. In the meantime, confidentiality is a short-term solution to ensure access to children affected by HIV/AIDS.

Furthermore, in some cases when teachers and classmates find out about their situation, the children get bullied by peers, discriminated by teachers or forced to leave school by other children's parents. Most informants in my study mention that discrimination and bullying causes some children to drop-out of school. This can be compared with a study from Namibia, where children were bullied because of their HIV-status (Baxen and Haipinge, 2015).

Community-based approach

Owing to the issues mentioned above, the informants support these children and their families in a number of different ways. Some informants favor community-based approaches such as strengthening the supportive capacity of the community by raising awareness through community-based workshops. Excluded groups face difficulties in accessing governmental resources in terms of nutritional support,

scholarships, monthly allowances, health insurance and treatment. Therefore, informants who work within government agencies focus on community-based services. For example, mobile testing of HIV and dispersal of HIV drugs at the commune level to enhance access to healthcare for rural communities and ethnic minorities. Similar strategies are found within earlier research. For example, Brazil implemented ambulatory-based care which cut mortality rates by 50 percent (Abadia-Barrero and Castro, 2006).

Rights-based approach

Other informants favor the right-based approach which focuses on educating the public and schools about equal rights to education. There are strong laws in Vietnam which makes it possible to sanction schools that discriminate children. Yet, based on my findings the government faces difficulties implementing these laws systematically because of corruption and social inequalities. Raising awareness about HIV is emphasized by all informants because lack of knowledge is said to be the number one reason for stigma. Another study reached a similar conclusion (Boggiano et al., 2014).

Awareness

Informants argue that awareness raising must be fun, interactive and connected to affected groups in order to give long-term results. On the contrary, Brown et al. (2003), claim that information and contact with affected groups do not change the experience of stigmatized persons, only the attitudes of unaffected people. Nevertheless, my findings suggest that documentaries, television talk shows and awareness campaigns led by self-help groups have shown significant improvements in public attitudes.

Empowerment

Additionally, some informants mention empowerment as an effective method which is aimed at the child adapting and coping with stigma. Instead of viewing these kids as victims, they are empowered to love themselves, be self-confident

and participate in society. Self-help groups aim at raising public awareness, supporting each other and create a positive image of people affected by HIV. These groups reduce self-stigma and promote social inclusion.

In conclusion, informants who work in NGOs mention that they empower vulnerable families through any kind of support which increase their children's access to school and academic achievements. This approach involves counselling, scholarships, monthly allowances and help with homework. Comparatively, counselling and self-help groups have shown positive results in Zimbabwe. Similarly, at a primary school in Tanzania group discussions and role-play made a significant change in the children's attitudes concerning people living with HIV/AIDS (Brown at al., 2003). These strategies correspond well with the findings of my study. My findings suggest that early provision of knowledge is essential in changing public perceptions and reducing stigma.

7. Concluding Discussion

7.1 Findings in relation to research aim and questions

The aim of this study was to gain a deeper understanding of the stigma and barriers which children with HIV face in regards to education in Vietnam and to analyze the strategies practitioners implement to promote equal rights to education and prevent stigmatization. In my study I have worked with a couple of questions in order to fulfill my research aim.

Firstly, I wanted to investigate the main challenges concerning access to education. *According to the practitioners, what are the main challenges for children living with HIV and how does stigma influence the children's access to education?* Based on my results, stigma is the greatest challenge for children living with HIV to access education. Stigma creates discriminatory processes. For example, these children are bullied and excluded from playing with others,

ignored by teachers, not allowed to participate in school and sometimes even forced to leave school due to parental protests.

Another question was: *What cultural and social meanings are tied to the social construction of HIV in Vietnam?* I found that HIV is used as a metaphor with many different social meanings. As such, HIV is associated with death, drug use and sex work. As a result, stigma is caused by the public's stereotyped beliefs about people affected by HIV/AIDS. These metaphors particularly degrade a person's moral character. However, perceived morality varies based on class and power. Consequently, stigma reinforces structural inequalities and reproduces oppression which further marginalizes an already excluded group.

Secondly, I wanted to explore: *How do practitioners work in order to prevent stigmatization and ensure equal rights to education for children living with HIV in Vietnam?* And: *Is the practitioners' work aimed at the children's adaptation and coping with stigma, or focused at developing knowledge and awareness/ understanding/ acceptance among the public and general population?* In this thesis I have found that practitioners in Hanoi implement extensive efforts to reduce stigmatization and ensure equal rights to education for children living with HIV in Vietnam. Their efforts are focused at the public to develop knowledge and awareness as well as aimed at the child adapting and coping with stigma. The government provides monthly allowances, health insurance and awareness campaigns. NGOs apply a community-based approach or a right-based approach. Their support includes communication, counselling, self-help groups, scholarships, documentaries and participatory-led awareness campaigns.

Lastly, I also wished to investigate: *What are the social and cultural barriers in preventative work and access to education for children living with HIV?* Apart from stigma, I have found that other social and cultural barriers severely limit access to education for these children. Such barriers are for example, poverty, corruption and inequalities in ethnicity, class, gender, geographical location and

orphan-status. Children affected by HIV in Vietnam are most often from poor families, ethnic minorities or they are the children of drug users or sex workers.

I would like to discuss briefly about social and cultural barriers. Because of a long history of war the society of Vietnam is very harsh. Income inequalities are growing due to vast economic growth. I believe this has created a strong survival instinct among people. The growing middle class distance themselves from the poor. Thereby, class distinctions have various meaning at different levels. Stigma is used by the elite to lock people into poverty and corruption severely limits participation of poor people. As a consequence, I would say that inequalities and corruption are huge barriers for these children to access education and not only stigma. The Vietnamese society is highly exclusive. I believe that more efforts must be placed on these underlying barriers in order to reach inclusive education.

In conclusion, it takes a long time to overcome stigma. Since stigma is a part of the social order and other social and cultural barriers preserve stigma. There must be interventions at different levels because stigma is a structural problem and not an individual issue. Empowerment is a buzzword with defuse meaning. Yet, empowering families means providing power to previously powerless groups. Empowerment entails increasing people's power and control over their own lives through participation. Participation is in fact a synonym for power since participation prevents social exclusion. There is a need for democratic participation, wealth distribution and elimination of corruption. These suggestions significantly increase the government's and practitioners' capacity to effectively implement stigma reducing strategies and ensure the right to education for children affected by HIV/AIDS in Vietnam.

7.2 Suggestions for further research

Investigating access to education for other vulnerable groups of children, such as children with disability, ethnic minority children or children living in poverty might provide broader support for the findings made in this study. Since stigma is multidimensional and affects different groups. Additionally, to conduct participatory research with vulnerable families about access to education would provide interesting comparisons.

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Appendix I

Linda Verngren, master student
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01232086743

Information letter

My name is Linda Verngren. I would like to interview you for my research. My master thesis is about access to education for children with HIV in Vietnam. Therefore approximately ten experts will be interviewed for about 45 minutes each. This project is conducted as a thesis for my master degree in Development Studies at Lund University in Sweden. The interview material will only be used for scientific purposes. I am committed to confidentiality and ethical considerations which are explained below.

Data protection requires your informed consent that I am allowed to use the information acquired from our interview for my research. Scientific procedures will be followed during my research which entails that the information you provide cannot reveal your identity:

• Special care will be taken in regards to interview recordings. These will be deleted once the analysis is completed.

• You will remain anonymous throughout the research process as well as in the final thesis.

• Your contact information will be deleted after the study. The signed consent form is only needed as confirmation of voluntary and valid participation. The interview transcripts cannot be connected to the signed consent form.

• Transcripts will be anonymous and will not be published. The anonymous transcript will only be read by my supervisor and translator who are also committed to confidentiality. I will use quotes in my thesis. However these quotes cannot reveal your identity.

• Let me clarify that non-participation does not bring any negative consequences. This means that you can choose which questions you want to answer (see interview guide). Participation is voluntary and consent can be revoked at any time.

I would very much appreciate your participation in my study. If you are interested, I would be happy to send you a copy of my thesis once it is finished.

Thank you for your kind support.

Appendix II

Letter of consent

The aim with this study is to gain a deeper understanding of the challenges children with HIV face in regards to education in Vietnam and how practitioners work in order to overcome these challenges.

Participation is voluntary and you will remain anonymous throughout the process. Confidentiality will be guaranteed. The contact information provided will be used only for possible contact after the interview for clarification.

You may at any time terminate the interview without reason. Your name is required only for valid participation. The interview data will only be used in this study and then deleted once the work is completed.

I hereby authorize Linda Verngren to have access to the material obtained during this interview. Furthermore, I also give my permission that the interview is recorded, translated and that notes are taken

YES ☐

NO ☐

Date	Email
______________________	______________________
Signature interview participant	Name clarification
______________________	______________________
Signature interviewer	Name clarification
______________________	______________________

Appendix III

Interview guide

Personal information
□ Male □ Female Age:_____________Education:_______________________
Profession:____

Challenges

1. What do you think are the main problems that influence access to education for children with HIV in Vietnam?
2. What is your opinion about children with HIV attending school?
3. Can you think of any problems and/or possibilities of children with HIV attending school?

Discrimination/ Stigma

4. How do you think discrimination influences education for children with HIV?
5. What do you think are the underlying reasons for HIV-stigmatization?
6. How do you think stigma/discrimination can be reduced or prevented?

Resources and strategies

7. How does your department/organization work to reduce/prevent discrimination?
8. How does your department/organization promote equal rights to education for children with HIV?
9. What do you know about other organizations and governmental agencies work to promote equal access to education for children with HIV?
10. Apart from support from NGOs and the government, what resources do you think are available to overcome these problems you mentioned?

Lastly
Is there something you would like to add?

Thank you for participating!

Appendix IV

Interview Protocol
Interview:

a) Who participated in the interview? (Interpreter?)

b) Under what circumstances did the interview take place? (Time, duration, room, arrangements)

c) Was there any disturbing factors? (Sound, stress, people)

d) How did the interview go? (Feelings, behavior, interaction)

e) Any specific events before and after the interview? (Greetings, something not recorded)

f) My opinions about the interview

- Any part of the interview that is particularly useful?
- What did the interview mean for the interviewee?
- Was the interviewee influenced by the surroundings?
- Concluding remarks