CHAPTER I

THE PROBLEM AND ITS BACKGROUND

Introduction

After the church services in 2006, a woman waited for all the church members to disperse. Then she walked forward to greet Pastor Girish Bokare of Free Methodist Church, Andheri East in Mumbai. With tears flowing down her cheeks the widow shared her story. It was the story of this woman and her child that inspired me with a passion which ultimately led to initiating meetings with people living with Human Immunodeficiency Virus (HIV). Over the next few years I was fully immersed in ministry with families living with HIV.

The woman personally was affected and infected with HIV and the youngest of her three children shared her fate too. As she continued her conversation with the pastor, she disclosed her status of being an HIV-positive person and burst into tears. She had contracted HIV from her husband who had passed away two years before, in 2006, and she was diagnosed with this tragic virus after his death. As her tears continued to flow, I wondered if the woman was stricken with the mental trauma of her physical ailment. But her prolonged conversations expressed the hard fact that her youngest son was deprived of being loved by the grandparents ever since the day he was diagnosed with HIV. She said, “I lost my husband two years back to HIV/AIDS and I was diagnosed with the same problem after that. The medical tests proved that my youngest boy was HIV-positive.

When I disclosed this fact to my in-laws, they started discriminating against me and my youngest son; we were driven out of our homes." The experience with this widow planted the seed that led me to design the research project described in this dissertation.

The reason I am writing about HIV is nothing other than a personal conviction that started in the year 2004. This disease is posing universal threat and has touched the personal lives of the millions who are now living with HIV. But apart from that, my personal attachment with this woman who visited Free Methodist Church at Andheri East Mumbai is a more powerful drive to have attempted this research.

Background of the Study

Mumbai**,** the largest city of India and one of the fastest growing metropolitan cities in the world, is the capital of Maharashtra, the second largest state in India in terms of geographic distribution. It is the fourth most populous city in world.[1] Maharashtra is located on the west coast of India, bordered by the Arabian Sea. Its neighboring states are Gujarat, Madhya Pradesh, Chhattisgarh, Andhra Pradesh and Karnataka. Formerly called Bombay, with a geographical area of 4,355 km^2, has an estimated population of 12,655,220, the most populous city in India.[2] Mumbai is situated in the west coast of India and has a deep natural harbor. It is one of the most prolific centers of film production in the world, known as Bollywood.[3] Urbanization is an issue that cannot be

[1] "Mumbai Population 2014," retrieved from http://www.indiaonlinepages.com/population/mumbai-population.html, accessed on 20th March 2014.

[2] "Mumbai Population 2014."

[3] Laya Maheshwari, "Why Is Bollywood Such a Powerful Industry? Mumbai Provides An Answer," available from http://www.indiewire.com/2013/10/why-is-bollywood-such-a-powerful-industry-mumbai-provides-an-answer-33491/, accessed on 17th June 2016.

dichotomized from the city being overpopulated. The city of Mumbai houses corporate headquarters of many multinational companies, provides business opportunities to millions of its dwellers, and is becoming the commercial and entertainment capital of India. Because of these facts, Mumbai attracts migrants from within and outside the country. Despite the great progress that is taking place, Mumbai is a city of contrast where "more than 1.2 million people or little under 10% of its population earn less than Rs.20 per day,"[4] which is less than half a US dollar. A great gulf exists between the rich and the poor in the city.

There is another, rougher side to the city's story of economic prosperity. Being the commercial and entertainment capital of India, Mumbai attracts immigrants craving economic security. These breadwinners, the male heads of households, are separated from the families and are highly prone to extra marital sex. Also, urbanization has led to overpopulation in the city, with 17 million people living in Mumbai, one million of them are the dwellers of Dharavi, known as Asia's largest slum, covering 170 hectares. It is home to100, 000 street children and more than 200,000 survivors of Human Immunodeficiency Virus and Acquire Immunodeficiency Syndrome.[5] Children are the most vulnerable group who easily fall prey to the growing problems of the city.

The number of people living with HIV in India is estimated to be 2.2 million. The first case of HIV was detected in Chennai in 1986. Across India, it is estimated that children below 15 years account for 6.54 percent and 40.5 percent of the total HIV

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[4] *The Times of India*, Sept. 1, 2009, retrieved from http://articles.timesofindia.indiatimes.com /2009-09-01/mumbai/28086355_1_capita-income-poverty-inclusive-growth, accessed on 18th July 2013.

[5] Patrick Dixon, *AIDS and You: Nowhere To Go* (Seconderabad: Operation Mobilization and AIDS Care Education and Training International Alliance, 2002), 329.

population infections are among women.[6] Despite the HIV/AIDS control measures taken, the growing statistics remain very significant. Maharashtra is one of the states with the highest prevalence in the country. The epidemic of HIV/AIDS was more concentrated in Southern and North Eastern States, which rapidly spread to the other general populations through the "bridge population."[7] Bridge population is the clients of sex workers, largely the truckers and single male migrants.

The stigma attached to this epidemic is a growing concern to be addressed with great care. This research aims to explore the stigma issues related to HIV/AIDS and its impact on children and to identify implications for church's holistic nurture of children and families infected and affected by HIV.

Statement of Problem

This study explores the question: What are the impacts of HIV related stigma on children infected and affected with HIV who participate in the Care and Share Project of Free Methodist Church, Andheri East, in Mumbai?

Statement of Purpose

The purpose of this study is to understand the impacts of HIV related stigma on selected HIV infected and affected children and their families involved with the Care & Share Project of Free Methodist Church, Andheri East, in Mumbai, how they perceive the

[6] "India HIV Estimations 2015-Technical Report," retrieved from http://www.naco.gov.in/upload/2015%20MSLNS/HSS/India%20HIV%20Estimations%202015.pdf, on 17th June 2016

[7] http://www.avertsociety.org/about-avert/district-level-organisation/maharashtra-state.aspx, accessed on 15th August 2012.

church's care for them, and to identify implications for the church's holistic nurture of children and families infected and affected by HIV.

Children with HIV being the respondents for this research, they will be the direct beneficiaries of this research. I am considering discussing the findings with the leaders of Free Methodist Churches in Mumbai and helping them understand how to be effective in its approach in ministering to children and families afflicted with HIV. The research questions that guide this study are as follows:

1. How do children infected and affected with HIV experience stigma?
2. How do children infected and affected with HIV cope with the stigma encountered?
3. How does the parent's experience of HIV stigma impact the children's experience of stigma and coping?
4. How do children and parents infected and affected by HIV/AIDS perceive the church as an agent of holistic nurture?
5. How do the NGO leaders, doctors and pastors in the study perceive the stigma experience of children and parents living with HIV and how the church can serve as an agent of holistic nurture for these children and parents?

Theoretical Framework

I have used Erving Goffman's understanding of stigma to draft a theoretical framework for this study. Goffman, a noted sociologist, describes stigma as "an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather

than in an accepted, normal one."[8] According to Goffman, stigma is a socially complex phenomenon that might affect the quality of one's life in many ways. Goffman presented the fundamentals of stigma as a social theory, including his interpretation of stigma as a means of spoiling identity. By this, he referred to the stigmatized trait's ability to spoil recognition of the individual's adherence to social norms in other facets of self. In addition to Goffman's theory, I have also chosen Robert K. Yin's case study method to understand these life situation phenomena in the society.

Yin claims that a complex life situation can be best studied through the case study method.[9] According to Yin, case studies that gather data from multiple sources, provide a rich source of data for understanding complex social issues in their context.[10] I used the case study method and key informant interviews to develop the research design and protocols. Figure 1 pictures the multiple sources selected in the study. Data collected from the multiple sources help understand the stigma as explained by Goffman.

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[8] Ervin Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Victoria, Australia: Penguin Books, 1963), 12.

[9] Robert K. Yin, *Case Study Research: Design and Methods*, 4th ed. (Thousand Oaks, CA: Sage Publications, 2003), 18-19.

[10] Yin, *Case Study Research*, 19.

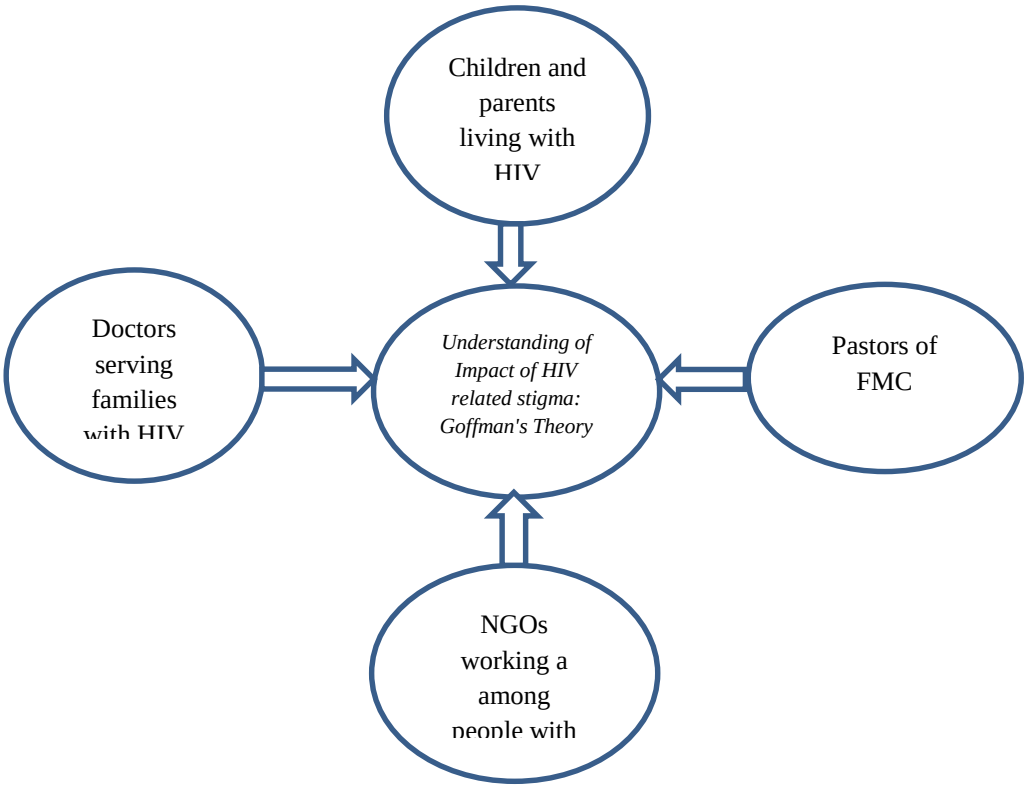

Figure 1: Impact of HIV-Related Stigma as adapted from Goffman's Theory of Stigma[11]

I gathered data from selected children living with HIV and their parents. I also gathered data from the key informants, medical doctors, Non-Government Organization (NGO) leaders and pastors serving families living with HIV/AIDS.

Further details of the design are discussed in Chapter III.

Conceptual Framework

The conceptual framework designed below shows the flow of the research process.

[11] Goffman, *Stigma*, 12.

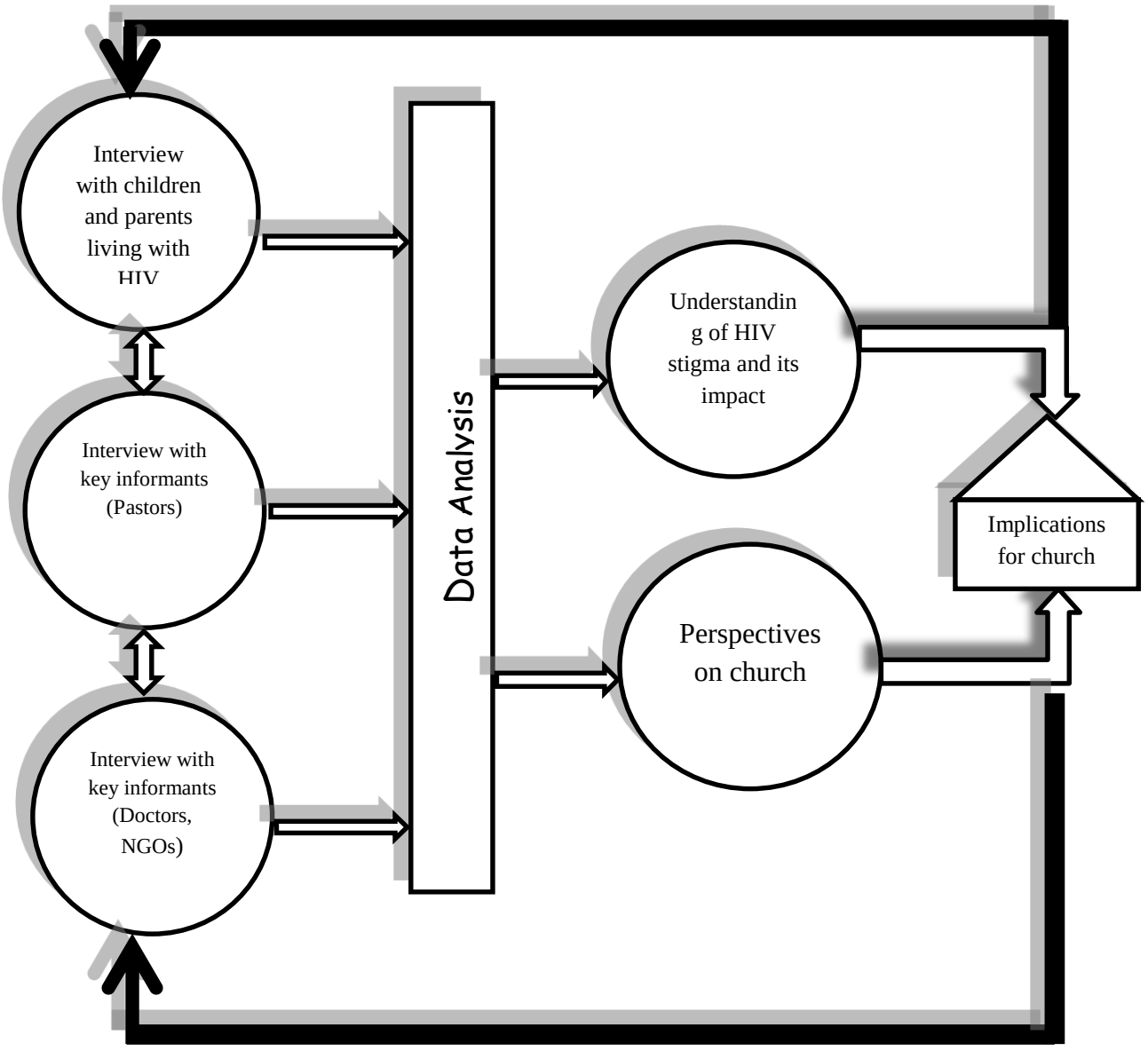

Figure 2: Conceptual Framework

The children infected and affected with HIV and their parents formed the first set of respondents in the case study framework. I further gathered information about HIV stigma from the key informants who are the non-governmental organization leaders, pastors, and medical doctors, who work among families living with HIV. The data collected from the respondents informed me with an understanding of impact of stigma and information on their perspectives of church. Further these findings led me to identify

implications for the church's holistic nurture of children and families infected and affected by HIV.

Significance of the Study

The study's significance lies in the fact that results obtained from this research will be presented to the Free Methodist Churches in Mumbai to motivate churches to be more effective in providing holistic nurture to the children and families living with HIV. Also recommendations are made at the end of the study for a long-term plan to be implemented in the Free Methodist Churches in Mumbai.

In my literature review I found a significant number of studies that focused on stigma experience of adults with HIV. However I found only a limited number of studies on stigma experience of children with HIV. This study adds to the understanding of stigma experience of children living with HIV and its impact on their lives.

Assumptions

This study has the following assumptions: first, the younger children participating in this study will require special methods to help them articulate their experience of HIV related stigma. Second, all the participants will be beneficiaries of Care and Share ministries. Finally, the implications will provide insights that can help the churches be more effective in the holistic nurture of families living with HIV.

Definition of Terms

AIDS is an acronym for Acquired Immune Deficiency Syndrome. Acquired means the ill health condition is acquired from external infectious factors. It is called

Immune Deficiency because the virus causing AIDS weakens the immune system of the human body thus leading to deficient immunity. Syndrome means that AIDS causes several kinds of diseases each with characteristic clusters of signs and symptoms.[12] The initial stage of degrading immunity leads to the state of AIDS.

Care and Share is the name of the project of Dayanand Foundation, an NGO of the Free Methodist Churches in Mumbai. The Care and Share meetings are held every second Thursday of the month, at the Free Methodist Church (FMC) Andheri. Nearly fifty to sixty families living with HIV belong to Care and Share project.

Dayanand Foundation is a registered non-government organization (NGO), which works purely on a nonprofit basis and is registered under the Bombay Public Trust Act, 1950 and under the Societies Registration Act, 1860 in Mumbai.[13] Dayanand is a Hindi construction of two words, "Daya" meaning mercy and "Anand," meaning joy. This foundation's stated goal is to serve the community with mercy and joy. It works with a vision to build peace in communities, restoring joy, justice, and equality through service with love and integrity.

Families living with HIV/AIDS refers to the families in which at least one member is infected with HIV, but other family members may only be affected by the presence of HIV in the family. It could be children affected who live with infected parents or siblings.

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[12] Frank E. Cox, *The AIDS Booklet: What Is AIDS?* 3rd ed. (Chicago, IL: Brown and Benchmark, 1989), 7.

[13] Dayanand Foundation Booklet, Western Indian Conference of Free Methodist Church, n.d.

HIV is an acronym used for Human Immunodeficiency Virus. This virus invades and attacks the white blood cells in the body that are required to resist infections. The person infected with HIV gradually picks up infections and the disease develops into AIDS when the body has completely lost the immune power.

Holistic nurture. The word holistic is used in the present context to indicate welfare of the total person. Jaqueline Watson contends that an holistic approach breaks down the cultural barriers and builds up trust to develop new processes aiming to address the needs of the whole child. It is an increased commitment to child centeredness, an approach that could improve individual children's overall physical, social, spiritual and emotional well being.[14] Holistic nurture as derived from the above definitions is an approach that considers the whole being of a child.

Psychosocial needs. According to Linda Richter, Geoff Foster, and Lorraine Sherr, all people have psychosocial needs, especially "young children, whose brains, bodies, and social lives are developing. Psychosocial needs must be met for a person to be happy, creative, to belong in social groups, and to have hope for the future. When children face difficulties and deprivations, particularly when these are chronic or repetitive, they are especially in need of stability, affection, and reassurance."[15] Understanding this definition in the context of the stigma experience of children and families is essential for holistic approach of intervention.

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[14] Jaquiline Watson, "Every Child Matters and Children's Spiritual Rights: Does the New Holistic Approach to Children's Care Address Children's Spiritual Well- Being?" *International Journal of Children's Spirituality* 2, no. 2 (August 2006): 254-255.

[15] Linda Richter, Geoff Foster, and Lorraine Sherr, *Where the Heart Is: Meeting the Psychosocial Needs of Young Children in the Context of HIV/AIDS* (The Hague, The Netherlands: Bernard Van Leer Foundation, 2006), 14.

Stigma is the "attitude that sees the other person as reduced from a whole and usual person to a tainted, discounted one."[16] Blackman describes stigma as a "sign of being socially unacceptable, resulting in isolation, rejection, blame, shame, etc."[17] Based on Goffman and Blackman's definition, stigma is the attitude of looking down upon someone in a way that could lead to discrimination.

Scope and Delimitations of the Study

The study is focused on children infected and affected by HIV/AIDS and their parents in the city of Mumbai involved in the Care and Share project, a ministry of the Free Methodist Church in Mumbai. The findings of this study could provide significant insights for Free Methodist Churches in other larger Indian cities. The implications of this research would provide deeper understanding and raise significant questions not only to Free Methodist churches but also to other denominations. As the South Asia Regional Coordinator for International Child Care Ministries (ICCM), the child support ministries of the global Free Methodist Church, the findings of this research will be very helpful for my work in Nepal, Bangladesh and as I interact with other regional coordinators globally.

Overview of the Dissertation

Chapter II of this dissertation discusses the literature on the origin and spread of HIV/AIDS, HIV related stigma, and its impact on children and families. It will also explore biblical insights on stigma and the call for God's people to care for widows and orphans and to work against social injustice. Chapter III provides the reader with an

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[16] Goffman, *Stigma,* 11.

[17] Rachel Blackman, *HIV and AIDS: Taking Actions* (Teddington: Tearfund, 2005), 9.

understanding of the research methods used, and Chapter IV reports the findings of the research. The conclusions and recommendations that flow from the research are presented in Chapter V.

CHAPTER II

REVIEW OF RELATED LITERATURE AND STUDIES

This chapter discusses the literature and studies that are related to the issue of HIV/AIDS in Mumbai. Both foreign and local sources are discussed. The literature reflects the epidemiology of the HIV and its various impacts on children and families living with it. All these factors will call the attention of God's people to a compassionate response on behalf of these marginalized children and families. The main topics of this chapter include the following: understanding HIV/AIDS; the impact of HIV/AIDS on children and families; studies on HIV/AIDS related stigma, the concept of stigma in the Bible, the biblical mandate for children and families living with HIV/AIDS, the New Testament Church as a model, the call to compassion as essential for HIV/AIDS ministry, and the Church and holistic nurture in the context of HIV/AIDS.

Understanding HIV/AIDS

HIV invades and attacks the white blood cells in the body that are required to resist infections. The human immunodeficiency virus has a profound ability to survive inside the body and so far nothing stops it. [18] The person infected with HIV gradually picks up infections and these develop into AIDS when the body has completely lost its

[18] Deborah Dortzbach and W. Meredith Long, *The AIDS: Understanding the AIDS Problem* (Downers Grove, IL: InterVarsity Press Books, 2006), 18.

immune power. Human immunodeficiency virus remains one of the most challenging global health issues, resulting in the deaths of millions of people. HIV/AIDS is causing debilitating illness and premature death for people at the prime of their life and has devastated families and communities worldwide.

The statistics read, "Over the past 27 years, nearly 25 million people have died from AIDS. In 2008, about 2 million people died of AIDS, 33.4 million were living with HIV and 2.7 million were newly infected with the virus."[19] Although everyone is susceptible, the commercial sex workers (CSW) and Injecting Drug Users (IDUs) are especially at high risk of contracting this tragic virus. Whatever may be the cause, as of 2007 there were approximately 700,000 people living with HIV in China, and more than 15 million children orphaned by AIDS.[20] The statistics of the UNAIDS indicate that, out of 36.9 million people with HIV in the world in 2014, around 2 million people were newly infected with HIV and 1.2 million people died of AIDS related diseases.[21]

The Origin of HIV/AIDS

Although the exact origin of HIV is still a debatable issue, it is generally believed that it can be traced back to Africa. HIV was first diagnosed in Los Angeles in 1981 among a few men who visited a certain medical practitioner. The following information

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[19] "Impact of HIV/AIDS," retrieved from http://www.globalhealth.org/hiv_aids/, accessed on 20th July 2011.

[20] Tao Xu and others, "The Situation of Children Affected by HIV/AIDS in Southwest China: Schooling, Physical Health, and Interpersonal Relationships," *Journal of Acquired Immune Deficiency Syndromes* 53 (February 2010): 28-30.

[21] "AIDS by the number 2015," retrieved from http://www.unaids.org/en/resources/documents/2015/AIDS_by_the_numbers_2015, page 5, on 19th June 2016.

is taken from UNAIDS History of HIV/AIDS.[22] A strange syndrome never noticed before, acquired immunodeficiency syndrome (AIDS) was first recognized as a homosexual or gay disease. By the time the virus causing AIDS was identified in 1983, it had killed thousands around the world, which went unnoticed. Among Western Countries, HIV was spreading predominantly by men who had sex with other men and by IDUs. By the 1990s in the United States, 57 percent of the AIDS infections were through male-to-male sex. By 1992, the spread of this epidemic had invited more public attention, as it was getting very clear that larger numbers of people were getting infected and affected.

When it began turning up in children and transfusion recipients, it became the turning point in terms of public perception. Up until then it was understood as a gay epidemic.[23] Between 1997 and 2001, HIV infection through homosexual contact started decreasing, while infection through heterosexual means was on a high rise.

There were a great number of people who were contracting HIV in Thailand and India in the late 1980s and early 1990s. Sex tourism was the primary way to contract HIV in the country in Thailand. In India, a high rate of HIV was found among the sex workers in Mumbai. Meanwhile, China also had 10 to 30 percent of IDUs infected. By the late 1990s there was a spread of HIV throughout many Asian countries.

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[22] "History of HIV/AIDS Epidemic With Emphasis on Africa," retrieved from http://www.un.org/esa/population/publications/adultmort/UNAIDS_WHOPaper2.pdf, accessed on 10th December 2013.

[23] Daniel McGinn, "MSNBC: AIDS at 20: Anatomy of a Plague, An Oral History," *Newsweek Web Exclusive*, retrieved from http://www.avert.org/aids-history-86.htm, accessed on 16th August 2012.

By the early 1980s, there was an extensive spread of HIV from West Africa along the Indian Ocean. Gradually growing towards the south, this epidemic was reaching towards Southern Africa and the data from UNAIDS shows that in the 1980s, South Africa had the largest number of people living with HIV/AIDS, that being five million.[24] By the end of 1985 there were many cases of HIV/AIDS around various regions in the world. It was during this time the first case of HIV/AIDS was detected in the state of Tamil Nadu in India among the sex workers. There were eighty-five countries across the world that had reported cases of HIV/AIDS to the World Health Organization (WHO). Victimizing the lives of thousands of people, HIV/AIDS was now posing threat to many countries across the world.

India is now considered as a country with low HIV prevalence, but according to the National AIDS Control Organization, India has the third largest number of people living with HIV/AIDS.[25] According to the HIV Sentinel Surveillance report, it is estimated that India has an adult prevalence of 0.31 percent with 23.9 lakh people (2.3 million, every ten lakhs make a million); infected with HIV, of which 39 percent are female and 3.5 percent are children under 15 years. Surveillance systems help in understanding the trends in the spread of HIV from various geographic regions across the country and thus help in the estimation of HIV infections in the country.

The number of annual HIV infections has declined by more than 50 percent during the last decade, 2.7 lakh (270,000) in 2000 to 1.2 (120,000) in 2009. Despite the

[24] "Workshop on HIV/AIDS and Adult Mortality in Developing Countries," retrieved from http://www.un.org/esa/population/publications/adultmort/UNAIDS_ WHOPaper2.pdf.

[25] "Annual Report 2010-2011," National AIDS Control Organization (NACO), retrieved from http://www.naco.gov.in/upload/REPORTS/NACO% 20Annual%20Report%202010-11.pdf.

declining trends among the young population, rising trends are also noted in some of the states. The four high prevalence states of South India are Andhra Pradesh, Maharashtra, Karnataka and Tamil Nadu and they account for 55 percent of all HIV infections in the country. People living with HIV in other states of West Bengal, Gujarat, Bihar and Uttar Pradesh account for 22 percent of HIV infections in India, and the remaining states contribute 12 percent of the infections in spite of their low HIV prevalence (NACO Annual Report 2010-2011).[26] The estimated number of deaths due to AIDS related causes is 1.72 lakh (172,000). However, the use of Antiretroviral Therapy (ART) on a large scale has resulted in decline of the number of people dying due to AIDS related causes.

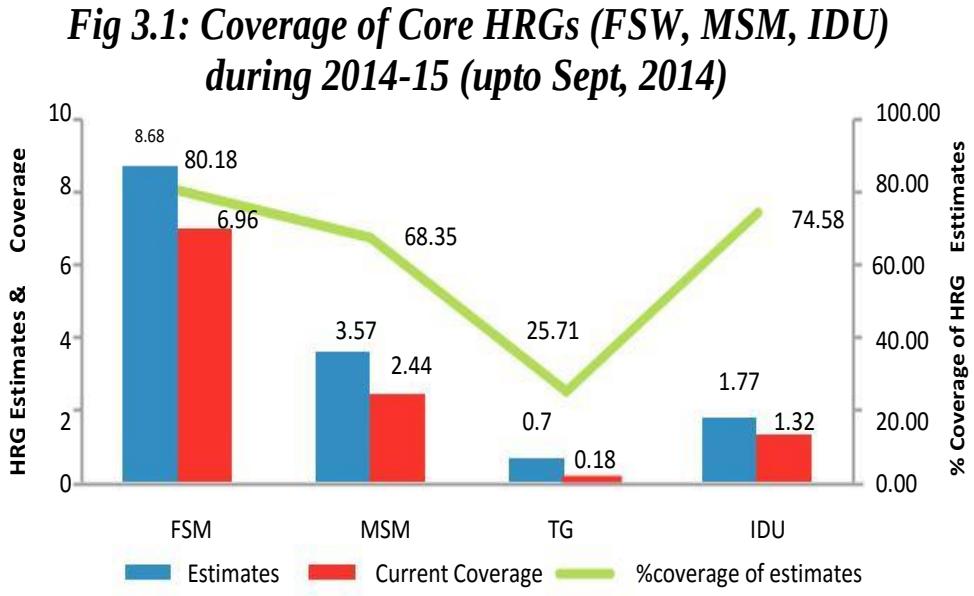

Figure 3: HIV Prevalence: India, 2014-15[27]

[26] "Annual Report 2010-2011," National AIDS Control Organization (NACO), retrieved from http://www.naco.gov.in/upload/REPORTS/NACO% 20Annual%20Report%202010-11.pdf.

[27] "Part B-NACO-Annual Report 2014-2015," retrieved from http://www.naco.gov.in/upload/2015%20MSLNS/Annual%20report%20_NACO_2014-15.pdf, page 405, accessed on 20th June 2016.

The overall HIV estimated prevalence according to Figure 3 varies by the High Risk Groups (HRGs), with 1.8 percent among the Injecting Drug Users (IDUs), 3.5 percent among male having sex with male (MSM) and close to 9 percent of HIV prevalence among the female sex workers. The data suggests that the primary drivers of the HIV epidemic in India are the commercial female sex workers, IDUs and men engaging in unprotected sex with other men.

The latest trends in India according to *Daily News Analysis* indicate HIV in urban areas is higher than in rural areas across India.[28] More persons above the age of twenty-five years contract HIV than persons in the age group between fifteen and twenty four. HIV prevalence among MSM (male having sex with men) in Mumbai is on the rise.

The Modes of Transmission of HIV

Since it is a virus, HIV can be contracted from a person already infected. It is deceptive because the infection cannot be detected immediately. The antibodies will be seen in blood test usually between 3-6 months after infection. This period is referred to as the window period, when the person is totally ignorant of potentially infecting other persons.[29] A person who is infected may show initial symptoms like flu and fever for two or three weeks. In most cases the patient may feel well after this episode with no other symptoms during which time the virus will seem to have disappeared. This is called the latent phase when the virus spreads to other internal organs like lymph nodes, tonsils and adenoid glands. This period of latency might range from few months to several years

[28] "AIDS on Wane, But MSM Still at Risk," *Daily News Analysis*, December 1, 2012, retrieved from http://www.dnaindia.com/india/report-aids-on-wane-but-msm-still-at-risk-1771981.

[29] Luke Samson and others, eds., *AIDS Care Manual* (New Delhi: Mosaic Books, 2000), 11-13.

depending upon a number of factors like general health, age, economic status of a person and even his or her access to health care.[30] The patient might develop other physical difficulties secondary to HIV, like loss of weight, prolonged diarrhea, extreme conditions of fatigue, rashes in mouth and throat, or easy bruising and bleeding.

The human immunodeficiency virus that causes AIDS attacks the CD4 cells that are vital for building up the immune system. When the virus enters the body, it constantly replicates producing copies of itself. The HIV locks onto the CD4 cells, later integrating itself into the host cells. Eventually a number of CD4 cells get attacked with the high rate of HIV replication and die. Once a person's CD4 count reduces to below two hundred, there is a high chance of opportunistic infections, which could be life threatening. The most dreaded opportunistic infection is tuberculosis.[31] The next stage can lead into a full-blown case of AIDS.

In terms of transmission, three major modes are recorded. The first mode of transmission is sexual transmission: unprotected penetrative sex with an infected person, male or female, that leads to contact with infected sexual body fluids such as seminal, vaginal or menstrual blood, poses a high risk of HIV transmission.[32] Ruptured skin or sores make an easy access point for exchange of body fluids for the transmission of the HIV virus and other sexually transmitted diseases.

The second mode of transmission is transfusion of blood and blood products: There is a great risk of contracting HIV if the blood is not tested for HIV prior to

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[30] Blackman, *HIV and AIDS*, 12-13.

[31] Samson and others, *AIDS Care Manual*, 18-19.

[32] Samson and others, *AIDS Care Manual*, 5.

transfusion. It is medically required to screen blood from all donors. Care must be given in using syringes, or while piercing skin, dental instruments, etc.

The third mode of transmission is mother to child transmission: There are three ways through which a mother can transmit HIV to her child. During pregnancy, the virus can cross the placenta and infect the fetus. When the baby is born, the child already contacted the mother's infected blood and then through breast feeding the body fluid contains a certain amount of HIV and gets into the child. There is a 15-25% chance of passing HIV to the child during pregnancy without anti-retroviral drugs.[33] There is a further increased risk if the baby is breast-feeding.

The primary mode of HIV transmission in India still remains unprotected heterosexual intercourse, 87.4%, second highest means of transmission is from mother to child, 5.4%, next highest is Injecting Drug Users, 1.6%, and homosexual activity accounts for 1.3% of the HIV infections as pictured in Figure 4.

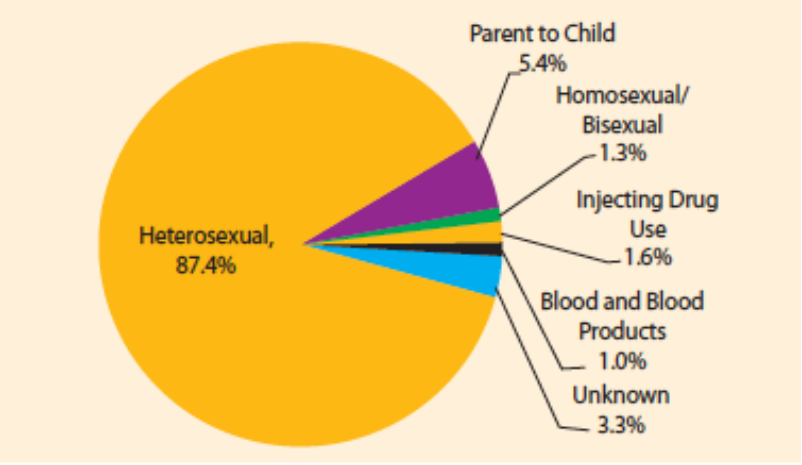

Figure 4: Routes of Transmission, India 2010-2011[34]

[33] Blackman, *HIV and AIDS*, 16.

[34] "Annual Report 2010-2011."

Detection of HIV and Its Treatment

Detection of HIV can be done only through the testing of blood samples. After the discovery of HIV in the year 1983, efforts to come up with adequate testing finally succeeded in 1985. In order to fight infection, the human body produces proteins called antibodies. The presence of these antibodies in the body is an indication of infection. In the case of HIV, it takes three months for the antibodies to develop and to be detected. There are a number of tests to detect the HIV antibodies, but the two most common ones are the Enzyme Linked Immuno Sorbent Assay (ELISA) and the Western Blot Kit Test.[35]

The patient who is tested positive for the presence of antibodies in ELISA test will have to undergo the Western Blot Test to be sure of the result of the previous test. The Western Blot Kit Test is a test of confirmation. A person is understood to be positive if the blood samples are tested positive in both ELISA and Western Blot Test. Due to the constant change in the HIV virus, it is classified into two types known as HIV-1 and HIV- 2. The most lethal form is HIV-1. It is commonly found in Asia, Southern, Central and East Africa, Europe and North America, whereas HIV-2 is commonly found in West Africa and India.[36] It has also been discovered that HIV-2 is less aggressive that HIV-1, and it is hard to detect HIV-2 in ELISA test.

The cure for HIV has not been found yet. However, false findings of traditional medical practioners have convinced some patients that they are completely healed of HIV and therefore no longer need their ART. This is life threatening for them. (Conversation

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[35] Samson and others, *AIDS Care Manual*, 13.

[36] Isabel Apawo Phiri, "Module 1-Gender, Religion and HIV/AIDS Prevention," in *Theology in the HIV/AIDS Era Series,* edited by Musa W. Dube (Geneva: World Council of Churches Africa, 2007), 7-8.

with an HIV patient, 2009). The treatment for HIV begins with the above-mentioned test and then will depend on the level of progression of the HIV virus into the blood cells, other symptoms, and on the opportunistic infections, if any. There are two ways of treating HIV/AIDS.[37] The first is by using Antiretroviral treatment (ART). It is the most basic treatment for people with HIV. This drug regimen stops the HIV virus from developing into Acquired Syndrome and slows down the spread of HIV. The other one is to treat the opportunistic infections with modern drugs or with traditional medicines. Antiretroviral drugs (ARVs) are very expensive so the government of India and other developing countries, with the help of WHO, have made policies to make this package of medicines available to those who cannot afford it.

Progression of the Disease

The progression of HIV/AIDS follows two patterns in children who are infected. In the first year of life, severe immunodeficiency develops in 15 to 20% of infected infants. Viral characteristics in infants appear to be related to the rate of disease progression.[38] Children with HIV suffer the usual childhood infections more frequently and more severely than uninfected children. These infections can cause seizures, fever, pneumonia, recurrent colds, diarrhea, dehydration, and other problems that often result in extended hospital stays and nutritional problems. Like adults with HIV infection, children with HIV develop life threatening opportunistic infections, although these infections vary

[37] Blackman, *HIV and AIDS*, 74.

[38] Stephane Blanche and others, "Relation of the Course of HIV Infection in Children to the Severity of the Disease in Their Mothers at Delivery," *The New England Journal of Medicine* (1994): 308-422.

from adults to children. The following are the diseases as described by National Institute of Allergy and Infectious Diseases:[39]

The first is *toxoplasmosis* (sometimes called 'toxo' for short). This illness is caused by a protozoan called Toxoplasma gondii.[40] Toxoplasmosis is seen less frequently in HIV-infected children than in HIV-infected adults, while serious bacterial infections occur more commonly in children than in adults. The second is *pneumocystis carinii* pneumonia (PCP). It is the leading cause of death in HIV-infected children with AIDS. PCP, as well as cytomegalovirus disease, usually is primary infections in children, whereas in adults these diseases result from the reactivation of latent infections. The third is a lung disease called *lymphocytic interstitial pneumonitis*. It is rarely seen in adults, occurs more frequently in HIV-infected children. This condition, like PCP, can make breathing progressively more difficult and often results in hospitalization. The fourth is *severe candidiasis,* a yeast infection that can cause unrelenting diaper rash and infections in the mouth and throat that make eating difficult. This is found frequently in HIV-infected children. Finally, as children with HIV become sicker, they may suffer from chronic diarrhea due to opportunistic pathogens.

Basically the line of treatment for pediatric HIV is the same as for an HIV infected adult, but the CD4 count and the age related issues are considered for drug

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[39] "HIV Infections in Infants and Children," retrieved from http://www.niaid.nih.gov/topics/hivaids/understanding/population%20specific%20information/Pages/children.aspxhttp://www.niaid.nih.gov/topics/hivaids/understanding/population%20specific%20information/Pages/children.aspx, accessed on 19th December 2013.

[40] "Diseases and Conditions," retrieved from http://www.mayoclinic.org/diseases conditions/toxoplasmosis/basics/causes/con-20025859, accessed on 16th May 2016.

metabolism to determine special formulations and treatment regimens that are appropriate for infants through adolescents.

The following information about the progression of HIV is taken from AVERT.[41] The stages that involve the progression from the initial stage are primary infection, clinically asymptomatic stage, symptomatic HIV infection and progression from HIV to AIDS. There is a large amount of HIV in the peripheral blood and the immune system begins to respond to the virus by producing HIV antibodies and cytotoxic lymphocytes, which is known as seroconversion.

The second stage that lasts for an average of ten years is free from major symptoms. Research has revealed that HIV is not dormant during this stage, but is very active in the lymph nodes. The third stage is symptomatic HIV infection where the immune system is severely damaged by HIV. The patient is put on antiretroviral treatment (ART) at once because of very low CD4 cells count. This is an indication that the immune system is deteriorating and the fourth stage is progression from HIV to AIDS. At this point, the immune system becomes more and more damaged and the individual develops more and more multiple infections and cancers, leading eventually to an AIDS diagnosis.

To initiate the treatment for children with HIV, there are three stages recommended: finding a child, testing a child and treating a child. Most children living with HIV become infected through mother-to-child transmission. ART should be initiated immediately to infants less than 18 months of age who test positive and the infant should

[41] "Stages of HIV Infection," retrieved from http://www.avert.org/stages-hiv-infection.htm, accessed on 19th December 2013. This organization has been at the forefront of the HIV response since 1986 and their work is mostly in Africa.

have a conclusive HIV antibody test at 18 months or 6 weeks after cessation of breastfeeding. The side effects of ART in children have to be identified and treated too with other medicines.

Impact of HIV/AIDS on Children and Families

Various factors determine the transmission of HIV/AIDS among children. Children can directly contract this tragic virus through infection via injected drugs or their vulnerability to high-risk sexual exploitation. As mentioned in the earlier paragraph, in most cases, children contract HIV from their mother. This section discusses four aspects in life that HIV/AIDS impact children and families: psychological, economic, social, and spiritual.

Children also often suffer the loss of their parents at an early age**,** if the parents are not well treated. The early loss of the parents may result in the children bearing heavy household responsibilities. Thus the children are deprived of their childhood innocent play and fun, and frequently become mini-adults carrying many responsibilities. Often a child is deprived of regular school attendance, joining in social gatherings, or even extended family occasions he or she must earning the money to support the family. This results in a growing number of children being head of their family.

An article presented by UNICEF echoes the condition of children living with HIV/AIDS all across the world. It reads:

> AIDS threatens children's lives. The impact of AIDS on children is both complex and multifaceted. Children suffer psychosocial distress and increasing material hardship due to HIV/AIDS. They may be pressed into service to care for ill and dying parents, required to drop out of school to help with farm or household work, or experience declining access to food and health services. Many are at risk of exclusion, abuse, discrimination and stigma.[42]

[42] "Children on the Brink 2002: A Joint Report on Orphan Estimates and Program Strategies,"

This suggests that a comprehensive understanding of the vulnerabilities of these children and adolescents should be carefully studied in the context of their families.

It is estimated that 37.2 million adults live with HIV around the world which means large numbers of children are affected by HIV even if they are not infected. They are affected by the illness and death of parents from AIDS. Children often experience discrimination that is associated with HIV or sometimes children become the wage earner for the family. One of the negative impacts of the global AIDS epidemic is the number of orphans it has created. In 2008, in India, 2.47 million Indians were living with HIV. Many children in India have lost their parents to AIDS and face a number of problems. They not only watch their parents die, but they are stigmatized for having been associated with HIV and AIDS and are forced to care for themselves and their siblings.

Children orphaned by AIDS have comparatively less chance of getting adequate education and proper health care. A particular case was of two children who were denied access to school in Kerala in the year 2003.[43] Two HIV positive orphans, six and eight years old, were denied accessed to schools because their parents had died of HIV. Addressing issues such as these are essential to the healthy development of children.

The Psychological Impact of HIV/AIDS on Children and Families

According to Richter, Foster and Sherr, the psychological development of young children depends on their ability "to be happy, creative, to belong in social groups, and to have hope for the future. When children face difficulties and deprivations, particularly

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retrieved from http://data.unaids.org/topics/young-people/childrenonthebrink_en.pdf.

[43] "Children on the Brink 2002."

when these are chronic or repetitive, they are especially in need of stability, affection and reassurance."[44] Since children are an integral part of the family, any member in the family with HIV/AIDS has an immense impact on a child. All the more if the child himself or herself is HIV positive. Anyone in the family infected with HIV will affect every member in the family and children suffer the grievous consequences of this epidemic. This suggests that HIV is in reality a family disease. The adult feels guilty for bringing this virus into the family, and the loss of any person in the family makes children feel guilty about it. For the child, there is as well a strong feeling of stigma and fear. Children easily pick up the attitudes of guilt and fear from the elders in the family. Most often in the case of a child who is HIV positive, the child "becomes a sponge for displaced feelings from parents and friends."[45] Such displaced feelings will affect the psychological and mental health of a child.

Moreover, Lorraine Sherr in the book, *Mental Health and HIV Infection, Psychological and Psychiatric Aspects*, discusses studies conducted among children living with HIV that indicate the children in the studies had developmental delay, cognitive deficits, language problems, loss of milestones, and also learning disabilities. [46] She further discusses that there is very little literature that addresses the multiple effects of HIV in children's lives. Quoting Forsyth in her article, Sherr states that "children in families with HIV infection were more withdrawn, and HIV positive children had more

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[44] Richter, Foster, and Sherr, *Where the Heart Is*, 14.

[45] Richter, Foster, and Sherr, *Where the Heart Is*, 66-67.

[46] Lorraine Sherr, "HIV Disease and Its Impact on the Mental Health of Children," in *Mental Health and HIV Infection, Psychological Psychiatric Aspects* (London: University College London Press, 1999), 43.

attention related problems."[47] Along with the attention related problems these children are likely to suffer behavior problems as the initial ramifications of being infected or affected with HIV. With the experience of stigma, guilt, fear, compounded with poverty, children will encounter disrupted nurturing in the family.

Sherr contends that HIV must be understood in the context of the family system. The mental health effects of HIV on children are very profound, but there is much less literature documenting the mental health effects than the physical health. It is necessary to see any actions taking place that will indicate "the need to sustain quality of family life and continuity of care as well as the need to support all family members before, during and after the many crises associated with the course of HIV disease"[48] Family, which is the basic unit of nurture for the child, must be provided with all care and support so the child is nurtured in all aspects of his or her development. Discussing the strengths of family care, Gill Grant mentions that childcare alternatives must be decided in the best interest of the child. Their differing needs could be mental, physical, basic needs such food, shelter and clothing, social needs such as being able to construct interactive networks, and spiritual needs which would allow them to explore and develop their faith.[49] The alternative could be institutional care for children, which also might be considered at the best interest of the child. But again the best interest of the child must be studied well enough so that the child would not land up in difficulty.

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[47] Sherr, "HIV Disease and Its Impact on the Mental Health of Children," 56.

[48] Sherr, "HIV Disease and Its Impact on the Mental Health of Children," 59.

[49] Bill Grant, "One or the Other-or Both? Child Care Alternative for Vulnerable Children," *The Chris Caba Journal* 2, no. 2 (September 2004): 5-8.

Jose Catalan, in *Mental Health and HIV Infection, Psychological and Psychiatric Aspects,* elaborates on the psychological problems in people with HIV infection. This disease apart from affecting the physical health of a person, has exhibited adverse psychological and social consequences of the sickness, too. Ever since the epidemic has been identified, the social stigma and the severity of its consequences are the indicators of how the society perceives it.[50] The author further observes that psychological problems can occur at two levels, firstly when the person is diagnosed with HIV infection and when the physical symptoms progressively worsen. Moreover in pediatric HIV, the child tends to suffer the consequences sometimes without the self-knowledge of the severity of the situation.

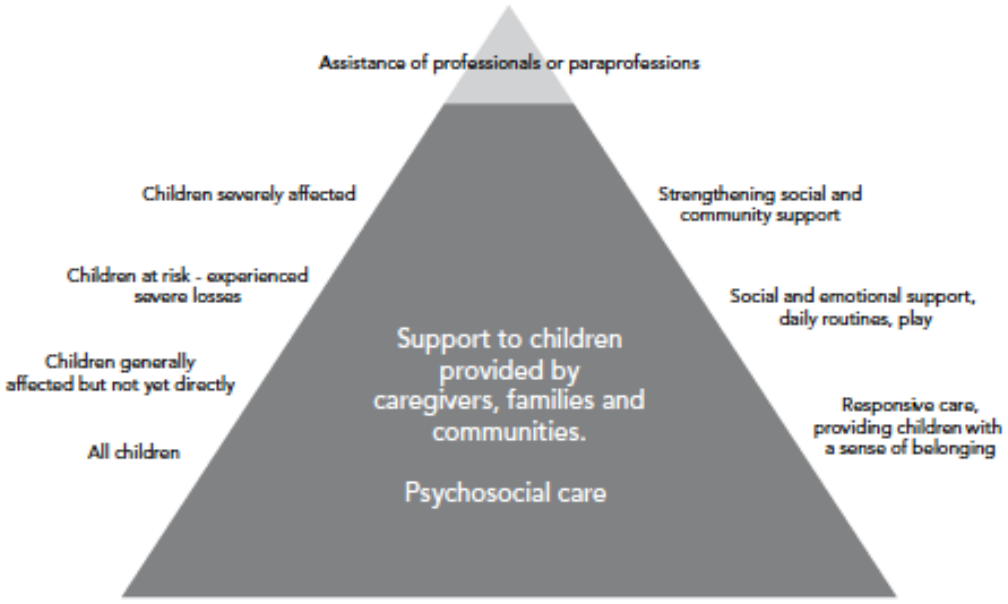

Figure 5: The Hierarchy of Children's Needs for Psychosocial Care, Support and Intervention[51]

[50] Jose Catalan, "Psychological Problem in People with HIV Infection," *Mental Health and* HIV Infection, Psychological Psychiatric Aspects (London: Univesity College Press, 1999), 21-22.

[51] Adapted from figure shown by Patrice Engle, Senior Advisor, Early Child Development, UNICEF at the second "Road to Toronto" meeting, held in Cape Town, South Africa; cited in Richter, Foster, and Sherr, *Where the Heart Is*, 30.

The components of this pyramid are similar to those of Abraham Maslow's hierarchy of needs where the first level of need begins with physical and psychological needs to be met.

The Economic Impact of HIV/AIDS to Children and Families

The reality of AIDS in our world is a most compelling issue. HIV not only affects an individual but the economy of the whole country is at risk. HIV/AIDS is a "problem with deep economic roots and potential devastating economic consequences."[52] The livelihood of the family suffers drastically when the breadwinner is woman. In Thailand the poorest and least educated are the most susceptible to AIDS and the economic shock they suffer is greater than that experienced by higher income and better-educated households.[53] Over the period of years the economically marginalized and the ill-educated people have been the potential targets of the deadly human immunodeficiency virus. In a study conducted in Thailand and India, David Bloom observed that HIV/AIDS has had a serious negative impact on the households, which was much greater than the direct loss of the household income.[54] There could be negative impact on the elders of the home, as their responsibility might have to be doubled with the loss of the income generating house member.

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[52] Amitrajeet A. Batabyal, "Asia: Comparative and Transnational," *The Journal of Asian Studies* 61 (August 2002): 1003.

[53] Batabyal, "Asia: Comparative and Transnational," 1003.

[54] David E. Bloom, "Introduction," in *The Economics of HIV and AIDS,* edited by David Bloom and Peter Godwin (Delhi: Oxford University Press, 1997), 4-5.

Driven by the low economic status and poverty in the Philippines, many Filipina women work outside the country where they are paid more than in their own country. The study entitled, "Breaking Borders, Bridging the Gap between Migration and AIDS," recorded in the book *Social Problems and Issues in the Philippines* explain that many of the young Filipina women working abroad experience forced sex and contract HIV.[55] If they were to choose to abstain from sex and to resist, it would leave them jobless, thus risking their economic stability. When they return home for vacations or for good, they bring the virus.

Forced by poverty and abuse some sex workers significantly women, take up the business of flesh trade on their own volition. Some families have sold their daughters to the agents who make promises of financial prosperity. Even today there are families who know no other way of surviving other than living on the income generated by forcing their young women into selling their bodies. During my visit to the brothel centers in Pune in the year 2007, one of the pimps said, "I earn a lot here and that is why I let my daughter also do this profession."[56] This shows the utter powerlessness of women and significantly children, in becoming prey to the human immunodeficiency virus which later develops into acquired immuno deficiency syndrome. A growing concern about girls being sold into prostitution is the impact of the HIV among them.[57]

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[55] Francisco M. Zulueta and Dolores B. Liwag, *Social Problems and Issues in the Philippines: Prostitution and Sexually Transmitted Diseases* (Metro Manila: National Book Store, 2006), 131-134.

[56] Personal conversation with the researcher, Pune, 2007.

[57] Joseph Gathia, "HIV/AIDS And Children In India," retrieved from http://www.countercurrents.org/gathia090708.htm, accessed on 13th December 2013.

The HIV/AIDS pandemic has a widespread and devastating impact on the economics of a community. In support of this statement Lisa Jackinsky states, "Bread winners become debilitated, lose capacity to provide for their families and must be cared for by others. Children are orphaned with little or no source of income, local economies shrivel as business close, jobs are lost, and available goods and services diminish."[58] This proves that HIV/AIDS is a dreaded disease, a socio-economic problem.

The situation in India is similar. The brothel keepers who are female sex workers train their children to be income generators. I made an attempt to find out the causes behind the women entering this flesh trade and discovered poverty as the compelling cause. The women who are the sole breadwinners live under economic pressure in the society. At one visit by the researcher to a brothel in Pune, near Mumbai, it was found that the women are into flesh trade to earn money to educate their children and meet the family expense. One commercial sex worker told me, "I am here because of my children; we were thrown out of our home after my husband died of AIDS and I contracted this disease here at the brothel." It is at the brothels that some women and young girls contract this terrible disease. Another HIV-positive woman who was rescued from the brothel explained that her uncle who was actually a guardian forced her into prostitution.

Blackman in her book *HIV and AIDS: Taking Action* rightly observes that the household will experience a direct impact if any family member has HIV/AIDS. It is noticed that, "for every person with HIV and AIDS, on an average, three to five people will be affected."[59] Due to the loss of the breadwinner, the economic burden falls on

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[58] Lisa Jackinsky, "Microfinance: Part of an Integrated Solution," *Global Future* (October 2005): 8-19.

[59] Blackman, *HIV and AIDS*, 21.

women the distribution of money on various needs might change as well. The share of money that might be spent on food, clothes, education or even recreation might need to be spent on medicine and the treatment of the illness itself. Also the earning member if sick might not be allowed to take frequent time offs from his or her job, thus might be forced to quit from the working place. At times such as these, the household will have to depend on fewer income sources. The household income will have direct impact on the education of the children. Most of the time children experience withdrawal or "children who are able to stay in school may have low achievement due to stress, lack of time to do homework, lack of encouragement at home, malnutrition and stigma at school."[60]

The Social Impact of HIV/AIDS on Children and Families

HIV/AIDS is not an exclusively health issue, rather in Africa this pandemic is tearing the families apart, breaking the functions of the communities and social developments. The farming and agricultural production has suffered great loss and ultimately the family responsibility has fallen on the women who are left to care for the family and sick spouse.

With the deteriorating health of the parents, children, especially the girls, are taken out of schools to take care of the family members.[61] The UN study in Zimbabwe found that "two thirds of the children were withdrawn from school because of HIV/AIDS

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[60] Blackman, *HIV and AIDS*, 22.

[61] Nigel Marsh, "Worse for Women: AIDS Exacerbates Gender Disparities," *Global Future* (April 2003): 12.

in their household were girls."[62]The children and women are the most vulnerable sectors of the society who are affected with every cause of evil forces.

This pandemic has been causing hardships to all, but it is more burdensome to women who remain the caretakers of the children. Nigel Marsh states that this pandemic "holds up to scrutiny the cultural, social and economic inequalities that render females more susceptible, both to transmission and to the spin off consequences of HIV/AIDS."[63] Stigmatizing women by the other family members will not only have severe impact on her, but also on the children who are dependent members of the family after the loss of the father.

Orlando de Guzman in his article**,** "The New Killing Fields," discusses social violence with women with HIV. He states that HIV/AIDS is a consequence of violence against women in Cambodia. The violence in the society most directly affects the women and children.[64] The women were forcibly raped as an act of revenge and thus contracted HIV. The men are socially more powerful than the women in the Cambodian society. The men at marriage are already sexually experienced when the women are expected to be virgins. As observed, men are not under any moral investigation as women were in their society. The men pay frequent visits to the brothels and contract HIV from the commercial sex workers. The wives and girlfriends are then infected with HIV from the men. Cambodia has the worst cases of this epidemic in Southeast Asia.

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[62] Marsh, "Worse for Women," 12.

[63] Marsh, "Worse for Women," 18.

[64] Orlando de Guzman, "The New Killing Fields," in *Drugs Death And Disease*, edited by Cecile C. A. Belgos (Quezon City: Philippines Center for Investigative Journalism, 2001), 71-73.

The same author further describes the spread of HIV in Cambodia as "an invading army sweeping across from West to East . . . from the Thai Border to Vietnam."[65] In Cambodia, Burma, Thailand and other South East Asian countries, the societies frown on the promiscuity of the women, but the immoral sexual behavior of men is tolerated or even encouraged. The social evils such as poverty, conflicts, powerlessness of women and children act as the social norms that contribute to the furtherance of the transmission of this virus. Therefore, "HIV/AIDS cannot be seen outside of the context of the social norms that shape human sexuality and social forces."[66] The spread of virus has resulted in various political and economic conditions.

A study done by Lawrence J. McNemee and Brian F. McNamee shows that ten percent of the urban residents and three percent of the rural population in Haiti were fatally infected with HIV/AIDS. This had posed great medical problems and the hospitals refused admission and treatment to AIDS patients in order that the limited medical facilities will be available for other pressing health problems.[67]The families end up nursing their infected relatives with minimal care and comfort without any access to physicians and medications.

Francisco M. Zulueta and Dolores B. Liwag , project the deadliness of the disease by calling AIDS a "microbial monster."[68] The HIV-positive survivors may look healthy

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[65] Cecile C. A. Balgos, Drugs, Death and Disease: Reporting on AIDS in Southeast Asia (Quezon City: Philippine Center for Investigative Journalism, 2001), 3.

[66] Balgos, *Drugs, Death and Disease*, 1.

[67] Lawrence J. McNamee and Brian F. McNamee, *The Nation's First Politically Protected Disease: HIV Transmission: The Unfolding of an Epidemic* (West Hills, CA: National Medical Legal Publishing House, 1988), 60.

[68] Zulueta and Liwag, *Social Problems and Issues in the Philippines*, 131.

and cheerful in their outer looks but they are internally downcast by mixed emotions of fear and agony. The virus has not only a devastating effect on the physical health of its survivors but it also causes "neuropsychiatric abnormalities or psychological disturbance caused by physical damage to nerve cells." As quoted in the book *Social Problems and Issues in the Philippines*, the study done by Dr. Loreto Roquero, the director of the National AIDS and Sexually Transmitted Diseases (STD) prevention says that the majority of the HIV risk could be from the six million overseas Filipina workers (OFWs), the majority of them being women.[69]. In the Philippines most of the men infected with HIV have acquired the virus from their sex partners, especially those involved in flesh trade. The religious institution condemns prostitution because it can spoil the image and reputation of the country.[70]Although the law enforces a penalty for prostitution, it is practiced with the corruptive measures in different pockets of the country.

The social acceptance of the HIV positive community is negligible. The women are the vulnerable victims of the social stigma from their families and societies. There are high suicide rates among the women who collapse under the pressure cast on them by their families, work places and the society. When they suffer multiple infections they become burdens to their family members. And therefore Patrick Dixon in his book *The Truth About AIDS* brings out the fact that some patients are admitted to the hospitals for social reasons, resulting in the collapse of support at home. Further, their families may not be supportive in giving care to the HIV patients."[71] It is the basic right of an

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[69] Zulueta and Liwag, *Social Problems and Issues in the Philippines*, 131.

[70] Balgos, Drugs, *Death and Disease*, 29.

[71] Patrick Dixon, *The Truth About AIDS, How People Become Infected*, 4th ed. (London: AIDS Care Education and Training International Alliance, 2004), 132-133.

individual to belong to a family and a home of one's own and the HIV patients are often deprived of their personal right.

Indian society is strongly family-oriented and the members have great affinities towards each other. The social stigma experienced by the HIV-positive member is considered as great shame to the family prestige. It must be recognized that "people exist not just as physical bodies but they live in a social world and AIDS must not be viewed just as a virus. Rather, HIV/AIDS is a complex, multifaceted social issue."[72] It affects the internal system of the societies and religious beliefs.

The Spiritual Impact of HIV/AIDS on Children and Families

The religiosity of an Indian community can be assessed by the frequent visits of the people to the religious temples and their avid participation in the religious rituals. Ezra Sargunam, an Indian author, states, "Indians at large have great capacity for belief and religion."[73] A woman will suffer rude allegations against her moral character when she is discovered to be living with the Human Immunodeficiency Virus. The public visitation of these women to any religious places is not socially accepted.

The majority of the HIV infected women in the Care and Share group selected to participate in this study are non-Christians, which makes their fate all the more complicated. During an interaction with a Muslim HIV positive mother of three children, she says, "my community was not willing to accept me when they understood about my

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[72] Rose Wu, "Poverty, AIDS and the Struggle of Women To Live," in *Health, Healing and Wholeness,* edited by A. Wati Longchar (Jorhat, India: Ecumenical Theological Education-World Council of Churches-Christian Conference of Asia, 2005(, 16.

[73] Phillip Elkins, "Strategy For India," In *Perspectives on the World Christians Movement*, edited by Ralph D. Winter and Steven C. Hawthorne (Pasadena, CA: William Carey Library, 1981), 13.

situation, but I feel very welcomed here at the Free Methodist Church." As Dan Brewster said, "Church is the only NGO that can be compassionate towards the suffering and the marginalized with the love of Christ."[74] The Free Methodist Church in Andheri offers a warm welcoming platform for children and families with HIV.

The democracy of India has given freedom of movement, right to seek employment, right to speak and act, right to bodily integrity, right to education, right to follow any faith of one's choice but "somehow . . . the religion does not support other liberties."[75] The women are deprived of their liberty in all ways in the society. The religious acceptance of a marginalized community in Indian society is negligible. Therefore the social services of the churches all over Mumbai and the whole of India could attract this community to be the recipients of the gospel message.

The dominating concept in Indian spirituality is the concept of *Karma.* The Hindus strongly believe in their good deeds earning them the reward of heaven. The good actions and the bad actions determine the very being of a person. "This process of life and death continues until *Mukti* (Salvation or liberation) is attained by good deeds."[76] Thus, the belief is, good deeds will make a person good and bad deeds will make one bad. *Karma* is the technical terminology for religious rites. That every sacred act produces its appropriate result is in the Vedic belief of Hinduism.[77] This common but foundational

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[74] Dan Brewster, "Child, Church and Mission Lecture Notes," 13th May 2010, Asia-Pacific Nazarene Theological Seminary.

[75] Martha C. Nussbaum, *Women and Human Development: The Role of Religion* (Cambridge: University Press, 2000), 168.

[76] K. V. Paul Pillai, *India's Search for the Unknown Christ: The Spirituality of the Indian Mind* (New Delhi: Fazl Publisher, 1979), 19.

[77] R. C. Zaehner, *Hinduism* (Oxford: Oxford University Press, 1962), 57-63.

belief of Karma is embedded deep in their hearts right from birth. One's fate is determined by the amount of karma accumulated. Troy Wilson observes, "according to the doctrine of *Karma*, there are necessary and sufficient conditions which account for the fortunes and misfortunes in the life of every living being."[78] Therefore ill fate is measured by the cause and effect of Karma. Every form of disease is seen as a consequence of one's bad deeds. The survivors consider HIV infections as a curse on themselves.

Having done a study on religion and HIV/AIDS, Nalini Tarakeshwar contends that, "unlike churches, Hindu temples or priests do not offer health services or discuss personal problems. Most prefer to think of Hinduism as something more personal and that has nothing to do with HIV."[79] Since others do not help them meet their spiritual needs they try to meet those needs on their own.

The Church must plan programs to integrate the concerns of those suffering with HIV/AIDS into the biblical teachings in the churches. The methods adopted in the churches to teach about HIV/AIDS must seek to "contribute towards prevention, provision of quality care, elimination of the stigma and discrimination of HIV/AIDS, as well as minimizing its impact."[80] Thus, churches will help families with HIV to live with dignity in the community.

Discussions of HIV/AIDS-Related Stigma

[78] Troy Wilson Organ, *Hinduism: The Religion of the Upanishads* (New York: Baron's Educational Series, Inc., 1974), 118.

[79] "AIDS and Hinduism in India," retrieved from http://www.beliefnet.com/Faiths/2005/08/AIDSHinduism-In-India.aspx?p=2#, accessed on 13th December 2013.

[80] Musa W. Dube, "Methods of Integrating HIV/AIDS in Biblical Studies," in *HIV/AIDS and the Curriculum,* ed. Musa W.Dube (Geneva: World Council of Churches, 2004), 15.

In the year 2004, there were three million children living with HIV and half a million died every year, although there is a slight decline after that till 2014 in mother to child transmission.[81] According to World Health Organization (WHO) in the year 2004 there were fourteen thousand new HIV infections per day; two thousand of the new cases happened among children less than fifteen years of age.

The 2008 United Nations General Assembly Special Session (UNGASS) Country Progress Report, India, states that several issues related to children living with HIV remain, and one of these is the stigma associated with HIV AIDS**.** A feeling of stigmatizing and being stigmatized thus creates a sense of great difference. Stigma and discrimination are mostly caused by misconceptions and ignorance regarding the spread of HIV/AIDS. Some common misconceptions about HIV include: HIV spreads through touching, kissing, sharing food, or even clothes with the person who is a carrier of this virus; Persons with HIV are of loose morals; there often seems to be a question of moral promiscuity; Having sex with a virgin can cure HIV; HIV can be cured by traditional medicines; NS HIV is an infection that creates fear and negative feelings about the person suffering, therefore, "stigma can result in people with HIV being insulted, rejected, gossiped about and excluded from social activities… stigma is often attached to things people are afraid of. Ever since the first cases of AIDS in the early 1980s, people with HIV have been stigmatized."[82] Because of fear of being stigmatized the infected people refrain from taking advantage of treatment, care and other facilities. During my

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[81] Dixon, *The Truth About AIDS*, 5.

[82] Roger Pebody, *HIV, Stigma and Discrimination*, 3rd ed. (London: NAM Publications, 2012).

conversation with a mother she said, “I do not want to tell my son’s school that he is HIV-positive.” Such a statement is an indication of fear of being discriminated.

Stigma defined by Izabel is “a negative assessment of a person or an action associated with a particular object or an issue.”[83] Stigma goes back to its origin in the Greek times. There were certain marks or signs made with hot branding iron on the body of a person who was caught in moral failures. Anyone who bore such signs of contempt used to be stigmatized in the Greek society and the stigmatized person lived in shame and contempt the rest of his or her life.[84] With respect to this definition, stigma of the people with HIV/AIDS can be better understood if not for the brandings irons. Phiri further contends that stigma is a social construct whereby the society coins for itself the moral code and classifies people into various strata.[85] Thus the society creates a judgmental attitude towards the stigmatized.

HIV/AIDS has been spreading across the economically disadvantaged people and causing a strong sense of stigma. Stigma can come from individuals, schools, and work place and it can also hinder the fight against HIV/AIDS.

Richard Parker and Peter Aggleton in *Journal of Social Sciences* noted that the “deleterious effects of HIV and HIV/AIDS related stigma has been voiced since the mid-1980s.”[86] Since the diagnosis of this epidemic, there has been a struggle to address the

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[83] Phiri, *Theology in the HIV and AIDS Era Series*, xi.

[84] Goffman, *Stigma*, 11.

[85] Phiri, *Theology in the HIV and AIDS Era Series*, 101-103.

[86] Richard Parker and Peter Aggleton, “HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implication for Action,” *Journal of Social Sciences and Medicine* 57 (2003): 13-24.

stigma, discrimination and denial associated with it. Parker and Aggleton quote from the address of Jonathan Mann, the founding director of World Health Organization, who cites three phases in the spread of HIV/AIDS. The first one is the advent of HIV infection which is a silent killer of families and devastates the community health, the second one is the phase of development of HIV into AIDS. This is sometimes delayed. The last he described as the most explosive phase which is the sociocultural, economic and political response to HIV/AIDS. This is identified by high levels of stigma.[87] Effectively addressing this stigma at the social, cultural, regional, national and international level is significant in the fight against HIV/AIDS.

In the year 2005, a family with three children was detected with HIV, and when the community in the province was made aware of this, their secret plan was to get rid of this impurity by burning the house of the family living with HIV. This heartbreaking story was personally related to me in the course of my research.[88]

Goffman speaks about three types of stigma; (1) The abomination of the body with various deformities (2) the *perceived* blemishes of individual character~~s~~, such as dishonesty, weak will, betrayal, treachery, addiction, unemployment and other negative feelings (3) the stigma of race, tribe or even nation.[89] In the case of HIV, all the three types of stigma exist, with an intensified measure of the second and the third type as mentioned by Goffman.

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[87] Parker and Aggleton, "HIV and AIDS-Related Stigma and Discrimination," 13-24.

[88] Maria Olivia Bating, "Stigma and HIV," Lecture Notes on 13th September 2012, Asia-Pacific Nazarene Theological Seminary.

[89] Goffman, *Stigma*, 14.

This third type of stigma is seen in casteism, which is practiced in the Indian society. The caste system is a system of social stratification and power that rules in Indian societies. Caste is an endogamous group or collection of groups, bearing a common name and claiming a common origin, "following the same traditional occupation and occupying the position of superior or inferior rank of social esteem in comparison with other groups maintaining a social exclusiveness with reference to diet, marriage and observing certain ceremonies and rituals."[90] People have mental divisions of caste system in the society.

Deriving from the observations within the Care and Share group of the Free Methodist Church in Mumbai, it is found that not one of the cases of HIV is from the upper class. There is a possibility that casteism may amplify the stigma issues related to HIV, since casteism itself cultivates stigma. Casteism would increase the issue of stigma related to HIV all the more and could be seen as compound stigma.

With respect to children suffering with HIV, this suggests that the mother who has transmitted the virus also transmits the stigma that goes with it. The mother's attitude of being stigmatized is passed on to the child. The child who is powerless and weak has no options to voice against the stigma he or she is facing along with the family.

In a study conducted in Mumbai, Kurien notes that the normal life of a person with HIV/AIDS is greatly disrupted because of the strong stigma related to the epidemic.[91] Typically the wife is blamed for the husband's death and often sent to her parent's home or even out of her home, and the children suffer the consequences. In the

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[90] Harish Babu, "The Caste System of India," retrieved from http://www.preservearticles.com/2012011620965/sample-essay-on-the-caste-system-of-india.html, accessed on 24th October 2012.

[91] A. K. Kuriakose, "Sociological Study of HIV/AIDS: A Case Study On the Role of Teachers in Prevention" (Master's Thesis, Mumbai University, 2010), 175.

same study conducted in Mumbai, it was found that teachers who worked in schools expressed their unwillingness to invite an HIV infected person or friend to a wedding or other family gatherings.[92] The stigma and discrimination of people living with HIV (PLWHA) is so strong that HIV survivors are treated differently even at hospitals.

HIV/AIDS related stigma as defined by UNAIDS (2007), is a process of devaluation of people either living with or associated with HIV and AIDS. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination is the behavior that results from stigma whereas stigma is the real experience of discrimination. This can lead to the violation of human rights that affect the wellbeing of people living with HIV. Stigma and discrimination related to HIV/AIDS also can mean less care and support to the people living with HIV (PLWHA) along with those associated with them. Thus it is observed that stigma and discrimination cause a tremendous increase in the personal suffering linked with the disease.

[92] Kuriakose, "Sociological Study of HIV/AIDS," 179.

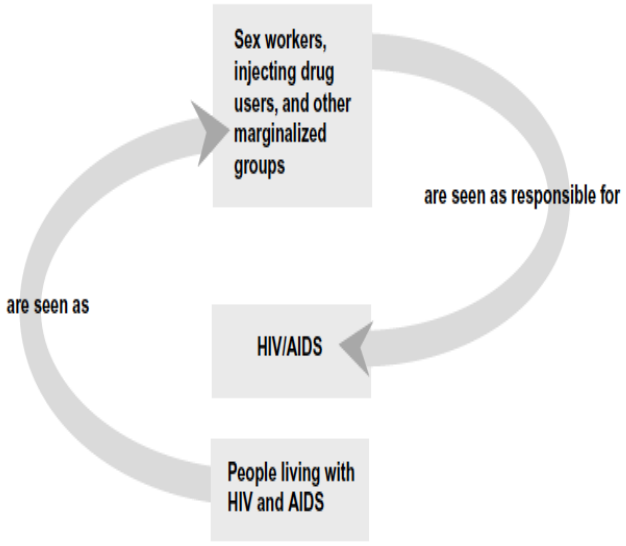

Figure 6: Circle of Stigmatization and Marginalization[93]

According to this cycle of stigmatization by Parker and Aggleton, the people who are living with HIV are considered either as sex workers or injecting drug users and also they are believed to be responsible for their infection.

UNAIDS reporting on "HIV-Related Stigma, Discrimination and Human Rights Violations" states from Parker and Aggleton that AIDS related stigma reinforces social inequalities. In reality this means that men and women are dealt with differently from each other when infected or assumed to be infected with HIV. A woman is more likely to be blamed even if the source of her infection is likely to be her husband. It is culturally and socially determined that women will be blamed for the transmission of sexually transmitted infections of all kinds. Therefore stigma is linked to power and dominion reinforcing social and gender inequality, thus creating a superiority or inferiority complex.

[93] Parker and Aggleton, "HIV and AIDS-Related Stigma and Discrimination," 13-24.

Keeping in mind all that is mentioned above, the question is how can the children and women overcome stigma, without the support of the family members? Joy Thomas and Ray Thomas aptly stated that stigma leads to financial hardship.[94] At times the mother may be pushed to the point of losing her working opportunities and or even fear of being stigmatized may cause a social withdrawal, resulting in financial instability for the family.

Various Studies on Stigma

Years after the onset of human immunodeficiency virus, HIV has evoked a range of frustration, fear, anger and loneliness in the lives of many who have suffered and are yet suffering. Various studies have targeted the issue of stigma reduction to some extent, yet stigma of this pandemic remains prevalent.

A study was conducted in Sao Paulo, Brazil from 1999 to 2001 on the experience of stigma in children of ages 1-15 years old. It was found that children's experience of stigma is impacted by racism, poverty, and inequalities in social status, gender and age. The findings state that the access to highly active antiretroviral therapy (HAART) in Brazil has created a powerful intervention in stigma reduction.[95] The patterns of stigma might even differ with the changes in economic status.

Stigma can be divided into "felt or perceived stigma and enacted stigma. Felt stigma refers to real or imagined fear of societal attitudes and potential discrimination

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[94] Thomas and Thomas, *AIDS: I'm Not At Risk Am I?*, 53-54.

[95] Cesar Ernesto Abadia-Barrero and Arachu Castro, "Experience of Stigma and Access to Highly Active Anti-Retroviral Therapy (HAART) in Children and Adolescents Living with HIV/AIDS in Brazil," *Social Science and Medicine* 62, no. 5 (March 2006): 1219-1228.

arising from a particular undesirable attribute, disease (such as HIV), or association with a particular group. Enacted stigma on the other hand refers to the real experience of discrimination. For example, the disclosure of an individual's HIV- positive status could lead to loss of job, health benefits, or social ostracism."[96] There was an incident in which I met a woman who was HIV- positive at Andheri Free Methodist Church. Being asked to submit her medical credentials after her job interview, she panicked because of her HIV status. Her fear was about losing her job. Felt stigma often causes people to develop strategies to avoid the occurrence of enacted stigma.

In a research study conducted by Brown, Trujillo and Macintyre, it was discovered that "HIV stigma is often layered on top of many other stigmas associated with specific groups as homosexuals and prostitutes and such behaviors as injecting drug use and casual sex. These layers of stigma have unfortunately helped to extend and deepen the AIDS stigma to many who are infected with or affected by the disease."[97] The study also evaluated the interventions taken to reduce stigma of AIDS or other diseases. The researchers found that the stigma reduction programs targeted other issues like awareness, tolerance, and treatment of HIV as well as the stigma reduction itself. In the case of low socio economic groups who are immigrants in Mumbai, HIV stigma may be layering on top of other stigma related to caste distinctions. The findings indicate that peer education, awareness programs, open discussion workshops and fostering acceptance through media campaigns are various means to reduce stigma.

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[96] Lissanne Brown, Lea Trujillo, and Kate Macintyre, "Interventions to Reduce HIV/AIDS Stigma: What Have We Learned?" Horizons Programme, Tulane School of Public Health and Tropical Medicine, 2001.

[97] Brown, Trujillo, and Macintyre, "Interventions to Reduce HIV/AIDS Stigma," 5.

Another study was conducted among one hundred and twenty educators in Kwasulu-Natal, South Africa. This study examined HIV related stigma both before and after two interventions, which were done to handle HIV related issues in the classroom settings. One intervention used was a very interesting CD ROM, "Everything you wanted to know about HIV/AIDS in the classroom, but were afraid to ask: a teacher's interactive journey."[98] The CD included video of an actor who played the role of a student afflicted with AIDS and how the educators would choose to respond to various situations related to HIV stigma. The educators were required to make their choices regarding confidentiality, first aid, universal precautions, and the educator/parent relationship. The second intervention was a workshop, which involved role-playing, lectures, and reflection on some materials. It was concluded that the care and support workshop and CD-Rom intervention were successful in reducing stigmatizing attitudes of teachers towards people with HIV. The results of this research state that stigma remains a major cause that can hinder improving the situation of HIV-positive students and educators. The individuals refuse to identify themselves voluntarily, because of the widespread stigmatizing attitudes prevailing in schools and society at large.

Research that was conducted in New Delhi, India, in three hospitals studied the strength and limitations of existing services for HIV/ AIDS infected individuals in hospitals. The purpose was to design approaches for motivating hospitals to become more "PLWHA friendly (People Living with HIV/AIDS)."[99] This study identified the causes

[98]Li-Wei Chao, Jeff Gow, Goke Akintola, and Mark Pauly, "HIV/AIDS Stigma Attitudes Among Educators in KwaZulu-Natal, South Africa," *Journal of School Health* 80 (November 2010): 561-569.

[99] Vaishali S. Mahendra and others, "Reducing AIDS-Related Stigma and Discrimination in Indian Hospitals," *Horizons Final Report* (New Delhi: Population Council, 2006), 8-12.

and manifestations of stigma and discrimination against PLHA by assessing the outcomes of the interventions related to staff knowledge, attitudes and reported practices. The findings suggest that misinformation and judgmental attitudes among all cadres of Health Care Workers were primarily due to misconceptions.

A comparison study was conducted in four countries, Tanzania, Zimbabwe, South Africa and Northern Thailand, to measure negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. The study presented an assessment of HIV/AIDS related stigma and discrimination in these four countries.[100] Negative attitudes and perceived acts of discrimination towards PLWHA and communication regarding HIV/AIDS were the two components analyzed. The results of this study determined that fear of stigmatization and discrimination were a barrier to HIV testing and that individuals who had never been tested for HIV were more likely to express stigmatizing attitudes. Also the health care workers have negative attitudes towards those who came to for antiretro viral (ARV) medicines. Individuals who had never talked about HIV/AIDS with anyone were more likely to hold negative attitudes about PLHA. Universal access to treatment for HIV and widespread understanding of ARV medications, HIV testing and open discussions of HIV/AIDS might reduce HIV related stigma and discrimination.

Ariane Petney conducted significant research in India to understand life stories involving stigma experiences of children.[101] The study was done in three different states,

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[100] Becky L. Genberg and others, "A Comparison of HIV/AIDS-Related Stigma in Four Countries: Negative Attitudes and Perceived Acts of Discrimination Towards People Living with HIV/AIDS," *Journal of Social Science* 68 (2009): 2279-2287.

[101] Arien Petney, "Experience with HIV/AIDs and the HIV/AIDS-Related Stigma Among Infected and Affected Children in India" (Master's Thesis, Heidelberg University, 2010), 6-10.

Kerala, New Delhi and Tamilnadu. Data was collected through case studies and in-depth interviews. It found that people living with HIV develop a state of insecurity and a sense of shame. This study suggested further need of such research; to promote understanding of the stigma experience of PLWHA. The methods that were employed in data collection were in-depth interviews of health care workers and case studies of thirteen children of ages six to eighteen.

The Concept of Stigma in the Bible

Since HIV/AIDS was not identified until the 1980s, reference to HIV/AIDS does not appear in the Bible. The Bible does, however talk about some diseases and sickness which were considered contemptuous. Johanna Stiebert mentions that the Hebrew Bible does talk about a disease that is parallel to HIV, which is leprosy, which was perceived to be inflicted because of disobedience to God.[102] One among the several words that is used in the Bible to mean to be sick or weak is the word *Chalah*, the use of the noun *deber* is to describe epidemic or pestilence and the most widely understood word meant for the use of the noun *deber* is to describe epidemic or pestilence and the most widely understood word meant for contagious disease is *tsara'at* to indicate some form of skin disease translated as "leprosy."[103] Sometimes in the Bible illness or diseases is seen as punishment from God, as in the cases of Pharaoh and the people of Egypt suffering plagues as the consequences of his refusal to release God's people (Exodus 10:1-20). The

[102] Johanna Stiebert, "Does the Hebrew Bible Have Anything to Tell Us About HIV/AIDS?," in *Integrating HIV/AIDS in Theological Programs*, edited by Musa W. Dube (Geneva: World Council of Churches Publications, 2003), 30-32.

[103] Stiebert, "Does the Hebrew Bible Have Anything to Tell Us About HIV/AIDS?," 33.

book of Leviticus also records various types of sickness among the Israelites as a result of their disobedience.

In the Bible, ill health is not only confined to those who deserve punishment, but it is also seen in the life of good people like Job (Job 1-2). God allowed sufferings to come into his life, including a severe disease. This was an implicit plan of God to confirm the faithfulness of God's people despite the sufferings they faced.

Leprosy in the time of Bible may be considered similar to HIV/AIDS today. Stiebert has observed that separation of the diseased person was commanded to prevent the spread of the disease.[104] The demand of Torah regarding the contagious disease was to alert others about the condition of the disease and prevent its further spread (Leviticus 13).

Stiebert helps interpret what it means for a person to be segregated. The Old Testament has a clear enumeration of caring for the sick and the diseased (Leviticus 19), but also the Hebrew Bible is very particular about being very alert in avoiding the spread of the disease. Those afflicted with leprosy were segregated to warn others and to avoid the spread of the disease, rather than for the purpose of putting the person to shame. Leprosy was a disease that was contagious through skin touch, and sharing of common items such as towels, plates, cups and other personal belongings. The transmission of HIV/AIDS can also be controlled by not sharing common needles, avoiding contact with infected blood, and by sexual abstinence.

In the article, "HIV and AIDS, Stigma and Liberation in the Old Testament," the authors Ezra Chitando and Masiiwa R. Gunda discussed the evidence of various

[104] Stiebert, "Does the Hebrew Bible Have Anything to Tell Us About HIV/AIDS?," 32.

"branding" as signs of stigma in the Bible. They identify signs, such as dietary stigma, shunning those who did not follow the dietary laws—as elaborated in the book of Leviticus (7:26-27, chapter 10), and stigma and health conditions (Leviticus 12, 13).[105] From their study of the Old Testament laws related to health conditions, however, the authors conclude that the laws were concerned about purity rather than inflicting stigma, shame and guilt. However often people in the community did stigmatize those suffering from the diseases such as leprosy.

People with leprosy are stigmatized and announced ceremonially unclean until they are healed (Leviticus 13). Men and women with bodily discharges were also considered to be unclean. Anything touched by a person considered being unclean or anyone who touches him or her would be pronounced unclean.

All these practices were related to ritual cleanliness and not moral or ethical issues. But Chitando and Gunda observe that the way people who were considered unclean were treated in Old Testament resemble the experience of people living with HIV/AIDS. The "combination of indigenous and Deuteronomistic attitudes (Deuteronomy 28:27-29) to illness led to stigmatization of people living with HIV/AIDS in Africa."[106] The aspect of discrimination in Africa came out of individual perception and from what is seen in Deuteronomy. It must be understood that in Leviticus, disease and illness were seen not as a consequence of immorality or disobedience. It is natural mishaps that cause uncleanliness requiring procedures of purification. The Hebrew

[105] Ezra Chitado and Masiiwa R. Gunda, "HIV and AIDS: Stigma and Liberation in the Old Testament," *Exchange* 36 (2007): 184-197.

[106] Chitado and Guda, "HIV and AIDS," 192-195.

scripture on health behaviors must not be misinterpreted to justify the social structures of stigma.

The societies of both the Old and New Testaments were patriarchal and men were elevated to positions of honor above women. In John 8:1-11 we see the injustice that can develop in patriarchal societies where this imbalance of honor exists.[107] The teachers of the law and Pharisees brought a woman caught in adultery to Jesus. After stating, "the law of Moses says to stone her," they asked Jesus, "What do you say?" These religious leaders brought only the woman; however, in Leviticus 20:10, the law called for the death of both the man and the woman caught in adultery. Does this suggest that over time, the woman became the one to bear the total shame and punishment of the adulterous act? In Jesus' response, we see his attitude toward men and women. To the male religious leaders Jesus said, "Let the one who has never sinned cast the first stone." The accusers left, without condemning the woman, and Jesus told her, "Neither do I condemn you. Go and sin no more. (John 8:10-11, NLT) Jesus called the men to acknowledge their sin, and showed grace and redemption to the woman.

India today is a strongly patriarchal society. In India if the man is put to shame, that means the honor of the entire family or the clan may be stripped away, on account of one man's actions. Honor/shame characteristics are very powerful in the Indian society, all the more strongly in the context of HIV/AIDS. What triggers the shame factor is the

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[107] The earliest manuscripts and many other ancient witnesses do not have John 7:53 to 8:11. A few manuscripts include these verses, wholly or in part, after John 7:36, John 21:25, Luke 21:38 or Luke 24:53; see John R. Kohlenberger, *NIV Integrated Study Bible* (Grand Rapids, MI: Zondervan, 2013), 1206. Even though this passage does not appear in some of the early manuscripts, it does give a beautiful picture of the attitude of Jesus toward women who were shamed by the religious leaders of His day.

attitude of people toward persons living with HIV/AIDS. Shame, fear and guilt are interrelated in any issue related to public image formation.

HIV/AIDS has left many women as widows. Why do the men prefer to commit suicides rather than to be alive for the sake of their families and to fight the disease? It could be inferred that they cannot stand the shame caused to their family through them, and so they terminate their lives. One of the male survivors of HIV/AIDS, the ministry beneficiary at the Free Methodist Church once confessed, "I am scared to disclose to my wife and my family that I am diagnosed as HIV-positive. My family members might throw me out of home."[108] Such an attitude of stigma is undoubtedly passed on to the children from HIV/AIDS infected parents, and eventually children themselves become the target of stigma at schools, and among playmates, consequently, they often withdraw from social interactions.

In the context of HIV/AIDS the society deals with the issue of shame by ostracism or discrimination and so the people living with HIV respond to this by retaliating against themselves. However as Paul Gilbert and his colleagues have observed, cultures and the societies define the characteristics that cause shame and honor. It is possible that what is shame in some cultures may not be in another.[109] In the context of Indian culture, the Hindi term used for honor or reputation is *izzat*, which could be personal or communal. The community sets norms that define shame in the society for individual.

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[108] This is during an informal conversation with the researcher on 15th December 2008.

[109] Paul Gilbert, Jean Gilbert, and Jasvinder Sanghera, "A Focus Group Exploration of Izzat, Shame, Subordination and Entrapment on Mental Health and Service Use in South Asian Women Living in Derby," *Mental Health, Religion and Culture* 7, no. 2 (2004): 109-130.

Biblical Mandate for Caring for Children and Families Living with HIV

Although there is moderate decline in the increasing number of HIV infected individuals worldwide, the pervasive problem of stigma attached to this illness still poses a threat in many societies. By establishing health centers in various areas of Mumbai, the government has been able to make good progress in providing free antiretroviral treatment to those living with HIV. What is most essential**,** however, is the help needed to elevate them from their marginalized status. The project manager of Inter Mission Care, one of the organizations that work with HIV/AIDS in Mumbai, has noted that there are people living with HIV who suffer silently, not knowing the sources of their next meal. These are the people not dying of HIV/AIDS but they are dying of hunger, stigma and rejection.[110] Those that are dying are not just statistics but are people who are to be valued.

The challenge of working with people with HIV remains enormous. According to AVERT 2010 many deaths go unreported in India due to high levels of stigma and discrimination. In many cases patients die with HIV having been diagnosed, but the death is attributed to other opportunistic infection**s** such as typhoid or tuberculosis is much more seen.

In the context of all that is happening around HIV, it is essential to establish grounds on which people can be valued and given voice. What the Bible has to say regarding care and valuing such people guides the principles of compassionate work among Christian NGOs. Many scriptural passages speak about caring for the sick, the

[110] Timothy Gaikwad, "Living with HIV in Mumbai, India," retrieved from http://www.theguardian.com/global-development/2011/jun/08/hiv-aids-india-timothy-gaikwad, accessed on 3rd July 2013.

poor, orphans, the widows and the other marginalized groups in the society. The Hebrew word for orphan is *Yathom* occurs forty one times in the Old Testament. "The orphan generally associated with the sojourner and the widow is the object of special concern. The quality of one's devotion is measured by how one treats the widow and the orphan."[111] The claim to love YHWH cannot be void of the love for the orphans. The God of the Old Testament had immense concern for orphans and the fatherless and so His expectation of His people for the orphans was also beyond measure. Those who mistreat the orphans and widows are equated with adulterers and scorners in Malachi 3:5. Justice implemented on behalf of those marginalized is seen as equivalent to reverence for God. At the bottom of the act of oppressing the widows, the poor and the fatherless, lies a heart of a person that does not fear God.

The Old Testament values the place of widows, orphans, and strangers in the Israelite community (Deuteronomy 16:11-12, 24: 17-22): "For the LORD your God is God of gods and Lord of lords, the great God, mighty and awesome, who shows no partiality and accepts no bribes. He defends the cause of the fatherless and the widow, and loves the foreigner residing among you, giving them food and clothing" (Deuteronomy 10:17-18, NIV). YHWH himself advocated for the orphans and widows who were a socially oppressed group in the community. And so were his devotees expected to seek justice and defend the orphans and plead for the widows (Isaiah 1:17). The orphans, the fatherless, widows and the aliens had part in the joyous occasion of the Israelites (Deuteronomy 16:11-12), occasions like Passover, feasts of the weeks and other festivals. The Lord intended an equal status for widows and orphans with others in the

[111] R. Laird Harris, Gleason, L. Archer, and Bruce K. Waltke, *Theological Wordbook of the Old Testament,* vol.1 (Chicago, IL: Moody Press, 1980), 934.

land of Israel. Any failure to give a portion to the fatherless or needy was to be considered as missing the commandments of God (Deuteronomy 26:13). It was to satisfy the needs of the marginalized members of the society that the Israelites were expected to give alms.

A great wrath awaits the one who perverts justice. One who withholds justice from the poor, aliens, orphans and widows will be cursed and so will be entitled to no goodness in the land of Israel (Deuteronomy 27:19). To be cursed was a very serious issue to be considered.

Isaiah illustrates YHWH's concern that religion be translated into practice. Speaking about Judah, Isaiah condemns the nation for her failure to put religion into practice. The rulers of Judah had little concern for orphans and widows (Isaiah 1:23). Religiosity was not translated into practice; rather the country's prosperity had come at the poor's expense. The Lord would avenge the nations, which did not defend the rights of the poor (Jeremiah 5:28-30).

Many biblical passages refer to the interest of God himself takes in the lives of the widows, orphans and the poor. In the Old Testament the word "poor" appears 142 times in the New American Standard Bible, which is transliterated as ***dal*****,** occurring very frequently as an adjective.[112] *Dal* depicts the lack of material wealth (Proverbs 10:15) and social strength (Amos 2:7). It is also used as reference to spiritual poverty (Jeremiah 5:4) and occurs parallel to need as in Isaiah 14:30. In contrast to the rich, the poor were devoid of wealth and power and thus lost their social strength.

[112] Archer and Waltke, *Theological Wordbook of the Old Testament*, 433.

The word poor also stand for the afflicted, *ani,* whom Israel is told not to oppress. In Deuteronomy 24: 14-15, the hired servant is described as *ebyon* and *ani,* who lives from day to day wages. These hired servants were socially defenseless and subjected to oppression.[113] The people are expected to give alms to the *ani* if they are to be blessed by God. God stands for the afflicted and is the protector and deliverer of the poor. Those who join with Him in delivering the poor from oppression will be blessed and considered as Godly (Ezekiel 18:17) and those who do not will be considered in the list of ungodly (Job 24:9). In most cases material deprivation resulting in social oppression and difficulty is in the minds of the prophets when they address the social injustice of God's people.

God has provided protection for the needy and poor in Mosaic Law by commanding that they be treated fairly and with justice. In Proverbs 30:14, the needy are described as those oppressed by the wicked and it is required by the rulers to minister justice to them. In designing the laws for the nations, God commanded that Israel would be fair minded in implementing justice to the needy and that the Israelites would not be partial or show favoritism. Old Testament teachings are rich in social sensitivity.

The Greek New Testament word for poor, *ptokos*, is related "to bowing down timidly," "being destitute," "begging," and it denotes "the complete destitution which forces the poor to seek the help of others by begging."[114] Paul in the book of Romans, speaking about Jewish piety, states that he takes great pleasure in extending his help to the poor and emphasizes showing mercy to the poor in the community (Romans 15:26).

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[113] Archer and Waltke, *Theological Wordbook of the Old Testament*, 1652.

[114] Gerhard Friedrich, ed., *Theological Dictionary of the New Testament,* vol. 6 (Grand Rapids, MI: William B. Eerdmans Publishing Company, 1968), 886.

According to the Epistle of James, true religion, which is acceptable to God, is defined in terms of care for the "orphans and widows in their distress and keeping. . . oneself from being polluted by the world (3:27)." As a mark of believers, God demands that we have compassionate hearts toward the orphans, widows, poor and needy.

Jesus demonstrated his compassion to people in need and called his followers to demonstrate compassion too: "Be merciful, just as your Father is merciful (Luke 6: 36, NIV)." The Greek word *eleos* and *splanchnizomai* used in the New Testament for compassion denotes the emotions aroused by contact with an affliction that comes undeservedly on someone else.[115] Compassion, love and care for the poor and needy are essential human obligations. This is affirmed by Walter Brueggemann when he says "Human obligation is rooted in a sense of divine commitment to the most vulnerable in society."[116] Having a deep understanding of divine commitment and human obligation will pave the way to a better perception of ministry to those in need.

In terms of working with the marginalized and downtrodden, many churches are more focused on nurturing their own. Sometimes there are compassion projects that are run in the name of love, but too often they are primarily meant to advance the reputation of the Church. God calls us to nurture not only our own children, but others outside the Church as well. Compassion is the only means of protection, which can wrap vulnerable children in the love of God. Knowing the God of the Bible must kindle our compassionate nature, for "the Lord is compassionate and gracious, slow to anger,

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[115] Freidrich, *Theological Dictionary of the New Testament*, 547-548.

[116] Walter Brueggemann, "Vulnerable Children, Divine Passion and Human Obligation," in *The Child in the Bible*, edited by Marcia Bunge, Terence E. Fretheim and Beverly Roberts Gaventa (Grand Rapids, MIL: William B. Eerdmans Publishing Company, 2008), 403-406.

abounding in love" (Psalm 103: 8, NLT). This is reinforced in the book, *Theology of Compassionate Ministry*, where Bryan Stone urges the reader to make a concrete commitment to those who suffer, who lack dignity, are marginalized, poor, oppressed and victimized.[117]

The New Testament Church as Model

In Acts 2, we see God's intention for the Church. Immediately after Pentecost, the believers "sold property and possessions to give to those who had need" (Acts 2:45, TNIV). These early Christians translated their faith into action. Those with resources willingly gave to support those in need**,** which was a magnanimous expression of their love for the Lord.

One expression of their generous love was the regular practice of providing for the widows who were culturally helpless. But in Acts chapter 6 we discover that in the distributions, the Hebrew-speaking widows were receiving more than the Greek-speaking widows. Discrimination had appeared in this well-intentioned ministry; however, the early church leaders provided a beautiful example as they listened to the concern of the Greek-speaking widows and took immediate action to correct the injustice.

Leaders in the New Testament Church worked towards eliminating elements of the social status that divided the new believers in the churches, but breaking down those divisions was not easy. Paul called the Jews and the Gentiles, the slaves and the free in the churches of Corinth, Galatia, and Ephesus to see themselves as one body (1 Corinthians 12:13, Galatians 3:28, Ephesians 4:4). And James challenged his readers to

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[117] Bryan P. Stone, *Compassionate Ministry: Theological Foundations* (New York: Orbis Books, 2006), 10-13.

treat both poor and rich alike. As noted earlier, he believed that equal respect and care for all was evidence of a genuine relationship with Jesus (James 2:1). These leaders in the Early Church followed the example of Christ, defending those who suffered social injustice.

Gary A. Haugen, the president of International Justice Mission, describes this world as evil, filled with despair, and oppression, and that these are powerful enough to victimize people into slavery and social injustice.[118] In a similar world of despair and oppression, the early church leaders were common Christians with uncommon courage; they were ordinary people with extraordinary faith who turned the world upside down.

Musa W. Dube explains HIV/AIDS as an epidemic driven by the several social inequalities such as "poverty (unequal distribution of wealth between the poor and rich), gender (unequal distribution of power amongst men and women), age (unequal distribution of power between the young and the older people), sexuality (unequal distribution of power between sexual identities), health status (unequal distribution between those who are infected and those not), ethnicity (unequal distribution of power between different ethnic groups).[119] Struggle against HIV/AIDS is a struggle against social inequalities in which those infected with HIV become powerless, silenced and incapacitated in their attempts to defend themselves. Today we need leaders of local churches who will follow the model of New Testament church leaders and work continuously against the inequalities faced by persons living with HIV/AIDS in the church and the community.

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[118] Gary A. Haugen, *Good News About Injustice* (Manila: Overseas Missionary Fellowship Literature, 2010), 67-77.

[119] Dube, *Theology in the HIV and AIDS Era Series*, 66-68.

In the context of HIV/AIDS the society deals with the issue of shame by ostracism or discrimination. The survivor usually responds to this by retaliating against oneself. However as Paul Gilbert and his colleagues have observed, cultures and the societies define the characteristics that cause shame and honor. It is possible that what is shameful in some cultures may not be in another.[120] In the context of Indian culture, the Hindi term used for honor or reputation is *izzat,* which could be personal or communal. The community sets the norm that defines shame in the society for the individual.

Call to Compassion: An Essential Component of HIV/AIDS Ministry

Christians are called to the ministry of caring and being compassionate to others. A ministry of compassion seeks to follow the word and ways of a compassionate God. As Michael Christenson, in his book, *The Samaritan's Imperative*, says, "Jesus redefined love and applied it to everyone. Love was not just a blood bond or an emotional connection to family and friends. Love, for Jesus, was a radical willingness to be merciful even to those you don't like; a deep compassion that desires the best for others, even those who hate you; an indiscriminate expression of concern for friend and enemy alike."[121] Jesus was radical in demonstrating his love for the marginalized.

Jesus touched the sick and healed them and by his intentional touch, Jesus cut down the social barriers that existed. In the words of Marshal Philip, "The God who responds to HIV/AIDS is seen supremely in Jesus of Nazareth, the incarnate Word of

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[120] Gilbert, Gilbert, and Sanghera, "A Focus Group Exploration of Izzat, Shame, Subordination and Entrapment on Mental Health and Service Use in South Asian Women Living in Derby," 109-130.

[121] Michael J. Christensen, *The Samaritan's Imperative* (Nashville, TN: Abingdon Press, 1991), 35.

God and the Lord of creation and history, who trod the dusty roads of Palestine."[122] He touched those who were sick with severe ailments, he had compassion on those that were hurt or alienated and stood for them. He gave purpose and meaning to those with no hope to be counted in their society.

Jesus, speaking to his disciples about the Samaritan, makes his point very clearly that how you treat people in need is more important than social and religious respectability.[123] The Priest and the Levite walked past the injured man on the road, but it was the Samaritan who stopped by the wounded man to care and nurse him.

Christensen assumes that the Samaritan chose to help the wounded because he himself knew how it feels to be ignored and left on the outside of the society. Ministry of love and acceptance is so very essential for those experiencing rejection from the society. By his genuine acceptance, Jesus befriended the outcasts, and demonstrated that the kingdom of God included those who were rejected.

Healing need not be a merely physical healing, but the totality of healing for the person, within and without. For this to occur, unconditional acceptance is essential. Christensen argues that "human beings require love and acceptance in order to survive in the world. We simply cannot live long in hiding or rejection…. When we love and accept people the way they are by including them in the life of the church people will open up and find healing."[124] This acceptance and inclusion brings healing to a person's sense of worth and dignity. In the words of Christensen, "true acceptance-defined as believing in a

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[122] Phillip Marshal, "Towards a Theology of HIV/AIDS," *Evangelical Review of Theology* 29, no. 2 (2005): 131-148.

[123] Christensen, *The Samaritan's Imperative*, 36.

[124] Christensen, *The Samaritan's Imperative*, 75.

person's worth, and potential-is received as emotional support, not moral sanction."[125] Therefore by expressing genuine acceptance towards people living with HIV/AIDS, Christians reveal their trust in the person's human worth, dignity, and potential.

Love and acceptance is an outpouring of God's compassion in the hearts of those who care for the sick and the suffering. Grigg in his book *Cry of the Urban Poor,* states that, "compassion means much love, a little response and great pain. Compassion is the heart of ministry. It is the source of identification. It is the wellspring of proclamation."[126] Compassion at times may be painful because often there is a great cost to be paid. The cost of ministering to the poor, the sick, and the marginalized may be undesirable and even hurtful.

Christensen believes that there are three stages a ministry to HIV/AIDS survivors goes through and therefore it takes considerable time to establish the ministry. The first of all is "responding to need and becoming AIDS sensitive and aware. The second is forming a mission group, and the third is developing specific programs targeted to particular needs."[127] Forming a mission group after responding to the need involves seven steps according to Christensen: sound the call, commit to the process, work through the issues, write a mission statement, nurture gifts for ministry, create a structure, and offer what gifts we have.[128] Working through all these seven steps takes time, however it is

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[125] Christensen, *The Samaritan's Imperative*, 76.

[126] Viv Grigg, *Cry of the Urban Poor* (Monrovia, CA: World Vision International, 1992), 84.

[127] Christensen, *The Samaritan's Imperative*, 96-98.

[128] Christenson, *The Samaritan's Imperative*, 98.

essential to work through these steps to be effective in ministry with people living with HIV/AIDs.

Christensen further emphasizes the ministry of presence as a call to compassion. Ministry of presence means to be simply available by being there with the sick, in this context, particularly the HIV/AIDS infected person. “Being there is the gift we bring to care-giving. Staying there is God’s part of the bargain.”[129] Planning to visit, writing out questions to ask, building trust, focusing on feelings of the patient and offering emotional and spiritual support constitute the ministry of our presence. It is interesting to learn from Christensen also about the ministry of absence. Activating a ministry of absence means to leave things in God’s hands for His divine intervention. Ministry of presence is in our limit, but ministry of absence, is absence of human power and allowing God’s intervention in the lives of people living with HIV. A caregiver in the context of HIV/AIDS is called to compassionate service to
deal with anger, depression, denial, and frustration.

The Church and Holistic Nurture in the Context of HIV/AIDS

To understand holistic nurture in the context of HIV/AIDS, the Church must have a comprehensive knowledge of what this virus is, the modes of transmission, and also prevention and care measurements. HIV/AIDS has devastated the lives of millions of children in many ways. As discussed earlier children are orphaned at a very early age following the death of parents. The children in many cases have to look after their parents, and often they themselves are suffering with the disease. Many of them are deprived of their privileges to be educated and to care for their own family. Stigma grips

[129] Christenson, *The Samaritan’s Imperative*, 120.

the child because of one in the family who is living with HIV, and this has devastating impact on the life of the child. These children need holistic nurture.

Dan Brewster in his book *Child, Church and Mission* reminds the readers that, "If our interventions are to be holistic, then, by definition, they must give attention to spiritual as well as physical needs."[130] It is observed that most of the non-governmental organizations and the health care services seem to leave out the spiritual essence in their approach to the social services. The Church has embraced services among the poor, providing them care, support and provisional services essential for children and families. Despite the ongoing ministries among the marginalized, the Church needs to step out even beyond their present efforts to bridge the gap that other non-government organizations have left. It is the responsibility of the Church to integrate a holistic approach of nurture, incorporating the physical, social, emotional and spiritual care into the communities with HIV/AIDS, especially with children.

Phyllis Kilbourn in her book, *Children Affected by HIV/AIDS*, rightly calls compassion the caregiver's garment, compassion as love in action.[131] The Apostle Paul encouraged Christians to be clothed with the garments of compassion, love, kindness, humility, meekness and patience (Colossians 3:12). Grigg states that compassion is "much love, a little response and a great pain. Compassion is the heart of ministry. It is the wellspring of proclamation. Its multiplication is the heart of Church growth. It is the motivation to seek justice."[132] When Paul encouraged the believers to be clothed with

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[130] Dan Brewster, *Child, Church and Mission: Resource Book for Christian Child Development Workers* (Makati City, Philippines: Church Strengthening Ministry, Inc., 2005), 41.

[131] Phyllis Kilbourn, *Children In Crisis: Contrasting Images of Childhood* (Monrovia, CA: Mission Advanced Research and Communication Center, 1996), 24-28.

[132] Grigg, *Cry of the Urban Poor*, 134.

compassion, he meant it to be an everyday, all the time expression of the Christian life and love. Being clothed with compassion in all of life will ultimately lead to seeking justice for the poor and marginalized in the society, including the children affected and infected by HIV/AIDS and their families.

Poverty has posed multifaceted issues in the lives of many living with HIV/AIDS. The acts of love, care and support on behalf of the people living with HIV/AIDS, are surely an attempt to demonstrate the way Jesus loved and cared for the people who suffered.

Caring for children in the context of HIV/AIDS must also include care and support to the mothers who head their families after the death of their husbands. Significant numbers of widows living with HIV/AIDS are voiceless and helpless. They are sole breadwinners of their families, but most often their health status impedes their ability to support themselves and their families. They may lose their jobs when their HIV-positive status is known, or as their deteriorating health does not allow for consistency in their jobs. When they lose their better jobs, they often turn to the sex trade to support their family.

With the compassionate act of the caring for the widows the Church transmits a message of love to the children. As a caring and loving body of Christ, it is essential to assist people in recognizing their own worth and in developing self-esteem. Stephen R. Covey emphasizes that it is an "essential ministry of the leaders of the Church to communicate people's worth and potential clearly in order that they may recognize these qualities in themselves."[133] Care, love, compassion and support extended to the children

[133] Stephen R. Covey, *The Leader in Me* (New York: Free Press, 2008), 41.

and families living with HIV/AIDS will boost their self-esteem, which is important to holistic nurture.

In the light of understanding compassion for children, it is important to recognize that God creates every child on this earth and in God's sight they have equal value. However**,** many children do not have the opportunity to develop that potential: to grow in wisdom and stature and in the favor with God and people as Jesus in his human nature grew (Luke 2:52). Brewster's vision of the church as the only non-governmental organization that can provide holistic nurture to the community has to be thought through carefully to keep the garment of compassion visible to the suffering and marginalized community.

Maria Cimperman has stated that theology and praxis cannot be separated in addressing the reality of HIV/AIDS. Theology and practical ethics are blended together and lived out in the dynamics of people living with HIV.[134] Therefore theology and ethics are remarkably inseparable.

The purpose of this study is to understand the impacts of HIV related stigma on selected HIV infected and affected children and their families involved with the Care and Share Project of Free Methodist Church, Andheri East, in Mumbai, how they perceive the church's care for them, and to identify implications for the church's holistic nurture of children and families infected and affected by HIV. The next chapter will describe the

[134] Maria Cimperman, *When God's People Have HIV/AIDS* (Mumbai: St. Paul's, 2005), 13-14.

research methods used to gain a deeper understanding of the impact of stigma on selected children and how the church can be more effective in providing holistic nurture for them and their families.

CHAPTER III

RESEARCH METHODOLOGY AND PROCEDURES

The purpose of this study is to understand the impacts of HIV related stigma on selected HIV infected and affected children and their families who are served by the Care and Share ministry of Free Methodist Church in Mumbai, Maharashtra, India, to also discern how they perceive the church's care for them, and to identify implications for the church's holistic nurture of children and families infected and affected by HIV. This chapter discusses the design of this study, selection of respondents, and the instrumentation for data collection.

Research Methodology

This study being qualitative in its approach, the case study method was used and data was gathered from children living with HIV/AIDS, their parents, key informant NGO leaders, doctors who serve these families, and selected pastors. This section briefly discusses the case study method, approaches for use with children, and the value of input from key informants. This methodology is designed to address the research questions.

The Case Study Method

Case study "is an intensive study of a case which may be an individual, an institution, a system, a community, an organization, an event, or even the entire culture"[135] Robert K. Yin observes that case study is an empirical study that investigates a

[135] Yin, *Case Study Research*, 23.

contemporary phenomenon in depth and within its real life context by relying on multiple sources of evidence in a triangulation form.[136] Using multiple sources of evidence to understand the complex social phenomenon, this method attempts to investigate the context in depth. He further claims that the case study method tries to answer "how" or "why" questions using multiple cases and is one of the best methods to address those questions.

In his book, *Theory and Practice In Social Research*, Hans Raj claims that "under the case study method, one case is undertaken and effort is made to make a comprehensive study of the problem in its entirety, keeping in view the unitary character of the subject."[137] This provides an in-depth study of the subject. John W. Best and James V. Khan describe case study as a "way of organizing data for the purpose of viewing reality, it examines a social unit as a whole, and a case study probes deeply and analyzes interactions between the factors that explain status or that influence change or growth."[138] Thus the case study method is the best approach to understand a social phenomenon. Thus the researcher has chosen to use the case study method because it is in line with the purpose of this study to understand a real life situation in depth and the important contextual conditions. I intended to do a case study because of the underlying personal conviction that every case is unique and intrinsic to suffice with deep insights to enhance learning.[139]

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[136] Yin, *Case Study Research*, 18-19.

[137] Hans Raj, *Theory and Practice In Social Research* (New Delhi: Surjeet Publications, 1979), 17.

[138] John W. Best and James V. Khan, *Research In Education*, 9th ed., Philippine ed (Singapore: Pearson Education South Asia, 2003), 249.

[139] Robert E. Stake, *The Art of Case Study Research: The Unique Case* (London: Sage Publications, 1995), 3.

This is a qualitative study using the case study method to gain insights into the experience of HIV related stigma from several perspectives, that of children, their parents, and key informants. The children and their parents, mothers in most cases, and the key informants interviewed for this study were all related to the Care and Share ministry, which works with HIV/AIDS affected families. The main reason I opted for this methodology is because as Robert Yin explains, case study is an empirical study that investigates a contemporary phenomenon in depth and within its real life context by relying on multiple sources of evidence in a triangulation form.[140] Therefore the case study is in line with the purpose of this study to help me understand a real life situation in depth in the important contextual conditions.

Research Approaches with Younger Children

It was important to help children in the study to express their experiences of stigma and their understanding of it. Therefore, three methods have been included in the interview protocol for the children to assist them in articulating their feelings and thoughts through drawing, story, and "family constellation." Drawings and stories were used with the younger children and the "family constellation" method was used for the older children.

First, drawing was used as a methodology for young children. Joyce Ofosua in her Master's thesis entitled, "The Role of Drawing in Promoting the Children's Communication in Early Childhood Education," claims that children use different forms

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[140] Yin, *Case Study Research*, 18-19.

of drawing media to articulate their inner feelings as well as processing their thoughts and also they use drawings to express emotional moments such as excitement and sadness.[141] She further observes that drawing can help children expand and communicate their own ideas and the discussions can retrieve their memories from their drawings. Discussing the role of drawing in depicting the spiritual journey of children, Catherine Stonehouse claims that drawing pictures of God can facilitate their thought process to share through their reflections.[142] In furtherance of the above statement Pablo Picasso in his article, "The Child as an Artist," claims that allowing a child to draw gives the child freedom to utilize creativity.[143] In the light of all these discussions about drawing, the researcher has opted for drawing as one of the research approaches for younger children. The younger children's explanations of their drawings were integrated into the narratives in Chapter IV of this paper.

Second, story was also used as an approach to gather information from children. The story of Raju and Rani (Appendix A) was told to the younger children of age 8-11. They were asked to listen to the story as narrated by me and respond to the questions following it.

Research Approaches with Older Children

With the 12-18 year old children, the "family constellation" method was one of the other interview protocols for case studies with children. The researcher has borrowed

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[141] Joyce Ofosua Anim, "The Role of Drawing in Promoting the Children's Communication in Early Childhood Education" (Master's Thesis, Sublin Institute and University of Malta, 2012), 9.

[142] Catherine Stonehouse, *Listening to Children on their Spiritual Journey* (Grand Rapids, MI: Baker Academic, 2010), 3.

[143] Pablo Picasso, "The Child as an Artist," in *Reclaiming Childhood,* edited by William Crain (New York: Henry Holt and Company, 2003), 84-85.

this idea of data collection from one of the early researches done in South India.[144] The research that was conducted in Kerala, one of the states in South India, studied the experiences of HIV related stigma of thirteen children.

"Family constellation" is a concept that was developed by a German philosopher and psychotherapist Bert Hellinger. "Family constellation" attempts to reveal the relation between the past and present problem which are said to occur when unresolved trauma has taken place in family, like murder, suicide, death of the dear ones, abuse, natural disaster, mental and physical illness, exclusion of family members and others.[145] Hellinger claims that "family constellation" is also an effective concept to reveal unconscious connection with the fates of family members. Apart from being used as methods to prompt children's expressiveness, it is also a therapeutic process that helps unhappiness, illness and failure. Therefore the researcher used small clay to make figures to depict each member of a family. The children were allowed to arrange a home/family scenario in the "family constellation" activity and then asked to explain the process. I recorded the observation and remarks of the children in this activity (see Appendix H for the Observation Checklist). The methods mentioned above are not for the purpose of psychoanalysis, but to assist the children to express their thoughts and feelings.

Key Informants

In qualitative research key informant interviews are in-depth interviews of people for their "first-hand knowledge about a topic of interest. The interviews were loosely

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[144] Arien Petney, "Experiences with HIV/AIDS and the HIV/AIDS-Related Stigma Among Infected and Affected Children in India" (Masters Thesis, Heidelberg University, 2010), 11.

[145] "Family Constellations," retrieved http://en.wikipedia.org/wiki/family constellations #cite_note-1, accessed on 17th July 2013.

structured, relying on a list of issues to be discussed. Key informant interview resembles a conversation among acquaintances, allowing a free flow of ideas and information."[146] Key informant interviews are conducted to get information about a pressing concern in a community and to discuss sensitive topics where the respondents are well informed and connected.

Another reason for using key informant interviews is to get information from people with diverse backgrounds and opinions. I chose NGO leaders and doctors as key informant because as professionals they see the impact of stigma related to HIV/AIDS from a different vantage point from that of the children or their parents. They are experts in the service to the community living with HIV. They also provide information to be explored in depth; in fact conversation with the key informants can reveal some intervention strategies too.

Another group of key informants were three pastors of Free Methodist churches. Since the research intends to understand how the children and families living with HIV perceive the Church as a holistic agent of nurture, I have purposively selected three Free Methodist pastors as key informants. There the researcher has purposively selected three pastors as key informant interviews. Understanding the pastor's perspective along with other respondents will give me insights for implications for the churches.

Selection of Respondents

[146] "Key Informant Interviews," Oasis Center of Substance Abuse Prevention's Northeast Center for the Application of Prevention Technologies (NECAPT), retrieved from http://www.oasas.ny.gov/prevention/needs/documents/KeyInformantInterviews.pdf, accessed on 16th August, 2013.

Selection of the respondents for this study was a very delicate step. Because of the fear of stigma and discrimination experienced by children and families living with HIV, the assistance of persons who are trusted by the families was of great help in selecting the respondents. It would not be an easy task to locate people living with HIV (PLHIV); as is mentioned in Azucena Patapat Hirahara's dissertation, they are "hidden."[147] I chose to draw respondents from the Free Methodist Church related ministries Care and Share and Jeevan Sahara Kendra. Jeevan Sahara Kendra is another NGO that is ministering to the families living with HIV in Mumbai. The social worker of the Care and Share ministries, who was trusted by the families were served by the ministries, provided me with a list of children and parents who he thought would be willing to participate in my study. From that list I selected the children who were of the ages identified in my research design. The Social worker also invited me to the Care and Share meetings where I began to build rapport with the children and parents.

For the case studies, six children infected and affected with HIV were selected from the ministry areas of the Free Methodist Churches with the help of social workers. The three age groups of children were 8-11, 12-15, and 16-18. The reason why I had chosen this age group is because they are preteens, young teens and older teens who may have different understanding of the stigma related to HIV. The three doctors were from Christian NGOs named Association for Christian Thoughtfulness, Jeevan Sahara Kendra and a doctor who helps with the HIV patients in the Care and Share project of Dayanand Foundation. Three NGO leaders were from Jeevan Sahara Kendra, HIV Consultant

[147] Azucena Patapat Hirahara, "A Christian Approach to HIV and AIDS in Thailand: Bridging the Gap Between Christian HIV Counselors and Counselees" (DMin Dissertation, Nazarene Theological Seminary, 2012), 58.

Forum and from Dayanand Foundation. I also selected three pastors, two from the Free Methodist Church and one from Baptist Church as key informants to understand how the pastors perceive the impact of HIV stigma on children and how the churches could serve the children and families living with HIV.

Research-Gathering Procedure

To begin this study I selected six children from different age groups: two respondents from each of the following age groups: 8-11, 12-15, and 16-18. Due to the sensitive nature of talking with people about HIV/AIDS, the social worker of Dayanand Foundation helped provide me with information regarding how much each child knew about his or her HIV status.

The second step that I did in the study was to obtain consent from the parents to participate along with their children in the research study (Appendix F). The interview protocols were pilot tested prior to the whole data collection. Three children and one mother were interviewed to be sure that the questions and the other methods were understood and were effective in stimulating the kind of data essential for the study.[148] Persons not included in the study were chosen for the pilot test. Interview protocols were refined based on the pilot test.

The third step that I did was to seek the help of the social worker of Care and Share ministry of Dayanand Foundation to set up visits with the families living with HIV. After making a few visits to be acquainted with the parents and to build rapport, mothers were interviewed at their homes using the protocol in Appendix B. Since the families are

[148] Yin, *Case Study Research*, 79-80.

very scattered through suburbs of Mumbai to the outskirts, I had a challenge to travel by train and bus to get to the participants' homes.

After the interview of the mothers, the children were interviewed using the self-designed instruments that are included in Appendix A. Since Hindi or Marathi is the language predominantly spoken by the research participants, the interviews were conducted in Hindi or Marathi as required, based on the fluency of the respondents. It was to my advantage that I was able to interview in either language because of my fluency in both.

The last step that I did in the study was to interview the three doctors (see Appendix C), three NGO leaders (Appendix D), and three pastors (Appendix E) who were the key informants for this research. Appointments were taken over the phone most of the time. I visited the doctors at their respective hospitals and clinics during their free time. It was all the harder because these professionals were very busy to grant me interview time. After obtaining prior appointments, I visited the NGO leaders to conduct the interviews. The last group of key informants interviewed was two pastors of Free Methodist churches and one from a Baptist church. Before I began to interview them, I had them sign the consent form (Appendix G).

Data-Gathering Instruments

I designed interview protocols to gather data from the children of each group: 8-11, 12-15, 16-18, parents of the children and key informants. All interview protocols are found in Appendices A to E. Since I was aware of the sensitivity of this study, it was important for me to build a comfortable relationship with the families before I interviewed them. After building good rapport with the families I interviewed them.

Data Collection and Analysis

I used voice recorder in the mobile phone to record the interviews. The data collected from children and parents were translated from Hindi/Marathi to English and transcribed. It took me five months to complete my interviews with all the respondents. Those transcripts provided the major data to be analyzed.

With regards to children's interviews, the children's drawings are imbedded in the presentation and analysis of data. Observation notes of the "family constellation" are also part of the data presentation. Apart from the case study notes, Yin suggests that data for case studies can come from direct observations, participant observations and physical artifacts.[149] Therefore I also maintained a record of direct observation notes of children's behavior and expressions and I have also integrated these into the presentation and analysis of data. I constructed a descriptive analysis of the data collected. The demographic and socioeconomic information of six children are displayed in a basic table format, and other themes rising out of the case study are categorized according to the research questions and presented accordingly. I also compared the data from all sources, looking for similarities, differences, and significant insights into understanding the impact of stigma associated with HIV/AIDS on children and families and how they cope with it.

Summary

This chapter has introduced the design of the study and required instrumentation used in the process to collect data. I have designed the methods and protocols in the context of the research guiding questions mentioned in Chapter I. The entire process of

[149] Yin, *Case Study Research*, 5.

data collection took me five months from November 2014 to March 2015. Many challenges like the distance of the respondents from my home, severe traffic problems in Mumbai urban area and sometimes the health conditions of the mothers were the matters I had to consider and reschedule my interviews accordingly. Using case study methods with descriptive analysis and observation of life experience provided rich resources for the study. The findings of the study are reported in the next chapter.

CHAPTER IV

PRESENTATION, ANALYSIS, AND INTERPRETATION OF DATA

The purpose of this study is to understand the impacts of HIV related stigma on selected HIV infected and affected children and their families involved with the Care and Share Project of the Free Methodist Church, Andheri East, in Mumbai, how they perceive the church's care for them, and to identify implications for the church's holistic nurture of these children and families who will be the direct beneficiaries of this research. This chapter presents the demographic characteristics of the study and the treatment of the sub-problems posed in the study.

A case study research method was used. Data was gathered from several sources to help understand the impact of HIV stigma on children. Interviews were conducted with the children and family members, as indicated below, as well as key informants who are the doctors, NGO leaders and pastors. Six children living with HIV, two from each age group of 8-11, 12-15, and 16-18; five parents and one grandparent; and key informants: three medical doctors, 3 NGO project leaders, and three pastors, two from Free Methodist churches and one from a Baptist church. All the key informants serve the communities where the children and families live.

The data is presented according to the research questions stated in chapter one. The findings are presented as answers to the following questions:

1. How do children infected and affected with HIV experience stigma?

2. How do the children infected and affected with HIV cope with the stigma encountered?
3. How does the parent's experience of HIV stigma impact children's experience of stigma and coping?
4. How do children and parents infected and affected by HIV/AIDS perceive church as an agent of holistic nurture?
5. How do the NGO leaders, doctors and pastors in the study perceive the stigma experience of children and parents living with HIV and how can the church serve as an agent of holistic nurture for these children and parents?

Demographic Characteristics of the Respondents

To protect the identity of the participants, the following codes were used to identify the children and parents in the study: children: C-A, C-B, C-C, C-D, C-E and C-F; and parents: P-A, P-B, P-C, P-D, P-E, and P-F[150]. The following codes were used for the key informant interviews: pastors: PAS-A, PAS-B, and PAS-C; doctors: D-1, D-2, and D-3; and non-governmental project leaders: NGOPL-1, NGOPL-2, and NGOPL-3.

Table 1 below shows the list of the six children in the study. They were all HIV-positive and all of them but one had lost their fathers to the deadly HIV virus. Most of the mothers are widows and have no means of livelihood. In the course of the interviews, I discovered the children are all on Antiretroviral Therapy (ART) for arresting the further growth of the virus.

All the children in the study live a great distance from Care and Share, the meeting place in Andheri East. They are able to come for the Care and Share meetings

[150] Note that P-F is a grandmother who is the primary care giver for Child C-F.

only occasionally when they are on holidays. Sometimes they are unable to come when they fall sick or due to some financial problems. Because their travelling to the Free Methodist church at Andheri for my interviews would be expensive for them, I arranged to travel to their respective homes. This also made it possible for me to grasp the picture of their residential area. Most of the children live with their mothers who are single parents. One child, C-F, is an orphan who lives with her grandparents.

Demographic Characteristics of the Children

Table 1 presents the information of the respondents in the study who are between the ages of ten and seventeen. The information I gathered consisted of where they are located, their HIV status, who they live with, their religion, and the name of the school that they go to. All the respondents in this study are HIV-positive. All of them are in school as well. Five of six respondents live with their mothers. The respondents come various religious backgrounds: Protestant, Hindu, Muslim, and Roman Catholic. C-E indicated coming from both Muslim and Christian backgrounds. These respondents have shared how HIV/AIDS have affected their lives in many ways.

Table 1: Personal Information of the Children

Case Code	Age	Gender	Location	HIV Status	Living with	Religion	School
C-A	17	M	Virar	Positive	Mother	Protestant	Mary Convent School
C-B	15	M	Shanti Nagar, Sahar Village	Positive	Mother and Grandmother	Hindu	Vidya Mandir
C-C	12	F	Borivilli West	Positive	Mother and father	Protestant	Borivilli Vidyapeet
C-D	13	F	Andheri West	Positive	Mother	Protestant	St.Blaise Convent

C-E	11	M	Goregaon East	Positive	Mother and father (live in)	Muslim/ Protestant	St. Joseph School
C-F	10	F	Sahar Village	Positive	Grandmother	Hindu	Vidhya Mandir

Demographic Characteristics of the Children's Parents

Parents also were part of the study. The reason to have chosen parents is to substantiate the data collected from the children. Sometimes what the children had left out, parents could provide in their response. Table 2 provides information about parents of the children who were interviewed. All the mothers in the study were HIV-positive. P-F is the grandmother of a 10-year-old child C-F and is her primary caregiver. The grandmother's HIV status was not identified.

What is significant to understand from the table is the long years the mothers are living with HIV themselves and the challenge of caring for their children infected with HIV. Moreover most of the mothers have no means of livelihood because of their unpredictable health conditions, or sometimes they have lost their jobs because of the fear of the stigma of HIV in their work places. It is worth noting that these respondents have lived as HIV-positive for so long, 13 years being the shortest and 23 years the longest. Through ART, these people can continue to live despite the presence of the virus in their body.

Table 2: Personal Information of the Parents

Respondent's Code	Location	Serostatus	Means of Livelihood
P-A	Virar	Positive for 17 years	No regular work, sometimes as house maid
P-B	Sahar Village	Positive for 16 years	No work at present
P-C	Borivilli East	Positive for 23 years	No work, sick most of the time

P-D	Andheri West	Positive for 16 years	Babysitting
P-E	Goregaon East	Positive for 13 years	No work, sick most of the time
P-F (Grandmother)	Sahar Village	Unidentified	Grandfather works in a factory, lives with the family.

Living Conditions of the Children and Parents Living with HIV

Mumbai has been a growing and urbanizing city for many years. With the migrants flocking into the city for job opportunities, the population of the slum dwellers keeps increasing. Dire poverty, unemployment, over population and migration from rural areas are the factors contributing to the slum expansion. People live in a very small space. Quite often a whole extended family lives in a house that is only 250 square feet in size.

Slum dwellers face many problems. With poor toilet facilities, many of the children use open spaces like, street sides, under the bridge, near the railway tracks and other open areas. Children play near sewage waste and dump areas. The lack of sanitary facilities and practices lead to many of the communicable diseases

All of the respondents in my study live in the slums that mark dire poverty. It is noted by Deborah Jack and Nick Patridge that HIV and poverty are relationally cyclical. The situation of HIV creates an imposing demand on resources and at the same time the work ability of the person gets limited with the deteriorating health condition of the HIV survivor.[151] Facing the challenges of HIV and poverty, the people living with HIV (PLWHIV), my respondents live in unhygienic conditions.

[151] "Poverty and HIV 2006-2009,"retrieved from http://www.nat.org.uk/media/Files/Publications/Sep-2010-Poverty-and-HIV-2006-2009.pdf on 16th June 2016.

The homes of all my respondents are very small, built with cemented bricks and protected by tin asbestos sheets that absorbed the heat in the city. Walking through the meandering narrow lanes to their homes located in congested slums, I could not escape the stench of the open sewage pipes. In my interview at C-A's home, I spent three to five hours in his kitchen sitting on the bare floor and the scary part of my interview was the mice running around under the dirty sink, taking no notice of the people in the room. Having no choice of avoiding the food cooked by P-A in that kitchen, I had to eat at the end of my interview.

In another case, at the house of C-F which is only 12 by12 feet in size, I sat near the door on the floor for almost four and half hours for my interview with her and her grandma. I understood from the interview that C-F stayed with her grandma along with five other family members. A three-month-old baby was on the cotton sling which was held by a rod on the ceiling. Quite often I had to request the mother of the baby to rock the baby to sleep, so that my interview would not be interrupted. It was common for this baby to urinate through the sling which was dripping on the floor. Although the family lived in these conditions, the smell was difficult for me to tolerate during the long interview. This all the more worsened the atmosphere of my interview hour (smell again). The grandmother had recently undergone ~~a~~ major surgery and was just lying on the floor during the whole interview.

With my experience of interviewing the respondents at their homes, I was surprised at how the families were living in such unhygienic environments.

Demographic Characteristics of the Key Informants

Table 3 presents the information of the key informants; three were pastors from Baptist and Free Methodist churches, three were doctors who engaged in private practice, and three were NGO project leaders who were directly involved in caring for children and families living with HIV.

Key Informant's Code	Profession	Mission
PAS-A	Pastor	Baptist Mission
PAS-B	Pastor	Free Methodist Church
PAS-C	Pastor	Free Methodist Church
D-1	Doctor	Association of Christian Thoughtfulness (ACT)
D-2	Doctor	Personal Dispensary
D-3	Doctor	Bethany Hospital
NGOPL-1	Project Leader	Dayanand Foundation
NGOPL-2	Project Leader	Jeevan Sahara Kendra
NGOPL-3	Project Leader	HIV Consultancy
Key Informant's Code	Profession	Mission
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NGOPL-3	Project Leader	HIV Consultancy

Table 3: Personal Information of the Key Informants

The data was collected through the case study method primarily. As noted in chapter III, I used different interview protocols for the younger children than I used for the young adolescent children. The protocols were revised after a pilot study conducted prior to the data collection. Along with interviews I used the "family constellation" method in which the participants were asked to construct clay figures of their family

members on a small cardboard. This method was very effective for the 12-18 year old children. While constructing their family representation, they began to express their emotions and seemed able to process their hurts like anger and frustrations towards their family members or even toward their friends. The explanations that came out of this "family constellation" method were more emotionally enriching than the responses to interview questions. As I sat and observed them, I sensed their deep hurts and suppressed feelings.

Small children also participated in a structured interview to initiate conversation. In addition, storytelling and drawing methods were used with them. Children of the age group 8-11 years not only enjoyed drawing and coloring, but they were able to speak about their drawings. It was a spontaneous explanation. Even before I asked them any questions, they started talking about their drawings. They expressed themselves and named the feelings that were involved in their drawings.

Story telling was another effective method for the smaller children. The story of Raju and Rani (Appendix A) grasped their attention and they could identify themselves in the story. They began to relate their situation with the characters in the story and began responding to my questions in the interview. Since the story seemed to capture their hearts, they responded with all their emotions.

The parents and all the key informants were interviewed using in-depth interview protocols (See Appendices C to E). All the methods employed for the various respondents helped me with the findings relating to the five research questions. The findings in this section come from the interviews with the children, their parents or their

caregivers, and the key informants. The findings are organized according to the five research questions to be answered through this study.

The first research question stated below reflects the children's experience of stigma at various levels.

How Do the Children Infected and Affected with HIV Experience Stigma?

Children have helped me understand their experience of stigma. They did not often use the word "stigma" but used different terms such as "bad attitude," or "ill feeling" to explain the stigma they experienced in their families, schools, and with friends. This section will examine the experiences of stigma that the children of this study encountered in these three areas.

Experiencing Stigma in the Family

From some of the interviews it appears that one of a child's earliest experiences with stigma may be observing the rejection of their parent or parents by his or her extended family. At age eight C-A saw his "mom being treated badly by my uncle [his father's brother] and his family. Earlier when C-A's father was ill, his brother did visit him, but with a handkerchief over his face, interfering with normal conversation. C-B "felt very bad" because his "grandmother used to treat my mom very bad." When C-D's father died of AIDS her "uncle and his wife did not even come to the hospital." During his illness, C-D's mother pleaded with the uncle and his wife to help with the care of her husband, but they did nothing to assist in his care. In response to the story of Raju and

Rani (Appendix I A), two of the younger children, C-E (Age: 11) and C-F (Age: 10) remarked, "Raju and Rani would have felt very bad… because their mother would have thought. . . 'What will I feed them? How can I take care of them?'" Whether or not these children could identify the impact of stigma, they experienced pain and concern as they watched their parents suffer.

The children also directly experienced the rejection of their extended family. C-A (Age: 17) reported, "My dad's relatives asked their children not to mingle, not to get close to us…. They keep away from us and never talk nicely to us. So we also do not go to their home."[152] P-A expanded on the treatment her family received, "When we go to our village, even now my husband's relatives do not talk well to us, they do not allow my son to kiss them, hug them. So I tell my son not to kiss my little niece. I tell him to keep at a distance."[153] She gives her son these instructions because of her fear that they would receive additional discrimination if the family were to discover he had touched her little niece.

C-B's grandmother "put us out of our house. I don't know why." Then he and his brother "were sent to a hostel for our studies." The children wanted to be with their mother, but they were not given a choice. Both their father and their uncle died within a short period of time. "This was a very sad experience for us," C-B (Age: 15) shared. And during this "very sad experience" the children were away from the family in a hostel.

[152] Interview notes of Child-A, on 22nd November 2014.

[153] Interview notes of Parent-A, on 22nd November 2014.

C-E (Age: 11) commented that "when dad was alive, no one said anything against us, but now they are chasing us out of this village." Whether or not the children could name it, they had experienced the impact of stigma, the rejection of their family.

In the interview conversations the children and parents did not report extended family members using the medical terminology for HIV/AIDS. Other terms were used. C-A's uncles and their families felt that his family had a "serious disease." P-A's sister-in-law told everyone that she had a "dirty disease." Interviewees also mentioned that their families and the families of others are "scared that they might contract this sickness from us," (C-A) and were "scared of HIV" (P-A). The use of fearful, non-medical terms when referring to HIV/AIDS may very well contribute to the ongoing fear and misunderstanding of the disease, which in turn may contribute to the stigmatizing and rejection of family members.

Experiencing Stigma in the Community

In addition to the rejection that the children experience in their families, their experience of stigma in the community is also very painful. C-A (Age: 17), who has observed the rejection of his mother, realizes that people have hurtful attitudes towards those living with HIV. "We are seen as criminals,"[154]he stated. Such negative responses leave a bitter scar on young adolescents. Similarly, P-B reported that when people come to know about people living with HIV, the people in the community "don't even shake hands with us…don't even talk to us." The children further mentioned that the reason why people are scared is due to their ignorance and lack of knowledge. Even after much

[154] Interview notes of Child-A, on 22nd November 2014.

medical advancement, people tend to hold negative attitudes towards the survivors of HIV.

Responding to the story of Raju and Rani (Appendix A), the younger children reported that "they might have felt very bad," and "Raju's mother felt alienated." The fear of being discovered to be with HIV is so strong that if people come to know in the community, "they will keep the affected family at a distance, not many will talk to them," says C-D (Age: 13). In response to the same story, C-E (Age: 11) realizes that in the absence of their parent, "they are being chased out of the village."[155] Although living in a community, still fear grips children living with HIV.

Communities are comprised of people of different languages, cultures and economic background. The stigma experience of those living in urban and rural areas can vary greatly. P-B elaborates: "What will happen, what will they think, if they—people in the community—come to know about the family's HIV status?" How to face people is one great fear of those living with HIV. In a metropolitan city like Mumbai where people of various socio-economic backgrounds live together crammed up in a little space, it is a fearful experience to face people with the stigma families living with HIV go through. P-C adds, "The children are the most affected group, when they see their parents suffering, they feel left out of the community." The observation of P-C about children being most affected, was noted by Richer, Foster and Sherr that children absorb all that happens around them, significantly at their home[156].Quite often when the patients get sick, the

[155] Interview notes of Child-E, on 11th December 2014.

[156]Linda Richter, Geoff Foster, and Lorraine Sherr, *Where the Heart Is: Meeting the Psychosocial Needs of Young Children in the Context of HIV/AIDS* (The Hague, The Netherlands: Bernard Van Leer Foundation, 2006), 66-67.

family becomes nervous, thinking of the moment when they will need to explain the cause of the sickness to the people in the community. P-C gives a glimpse of this concern, "If they come to know (about my disease), they might not allow their children to play with my daughter."[157] Again the fear of facing discrimination in the community is as painful to the patient as the disease itself.

While recalling her own journey with HIV, P-A narrates the story of her friend and her children. Her friend's child saw his father's death as he was just left to die. Family members brought his food in a bowl and left it at a distance, causing the sick father to use his very limited energy in order to reach the food. The child witnessed the father's experience of stigma and eventually saw the death of his father. This is an especially sad situation in which the child had to journey through the stigma experience of his father until death. P-F, the grandmother of an orphaned child, says, "no one knows here about our problem of HIV or even about my granddaughter."[158] She believes that if they knew "they might spread the word and spoil our lives in the community." Fear not only rules the parents but also affects a greater circle outside the home. The words of P-F's fear of the loss that could result from disclosure is a concrete example of Brown's statement that HIV disclosure could lead to loss of job and social status.[159] P-F continued, "my neighbors keep teasing her, 'you are always sick, you are a sick child (*tu beemar hi*

[157] Interview notes of Parent-C, on 4th February 2015.

[158] Interview notes of Parent-F, on 30th December 2014.

[159]Lissanne Brown, Lea Trujillo, and Kate Macintyre, "Interventions to Reduce HIV/AIDS Stigma: What Have We Learned?" Horizons Programme, Tulane School of Public Health and Tropical Medicine, 2001. 50.

rahti hai). You can't play with us.'" The child who goes out to play experiences such derogatory remarks in the community.

PAS-A contends that, in the outskirts of Mumbai and in other areas of Maharashtra, the intensity of stigma will be surely higher than in Mumbai.[160] This is true because Mumbai is a metropolitan city with people from various cultures and social backgrounds. But in the villages, which are far away from Mumbai, the people living with HIV suffer a greater level of stigma than in cities like Mumbai. PAS-B, a person rich in ministry-experience to HIV-positive persons, observes that "HIV discrimination makes it all the more complicated and difficult for children and families in community because of the already existing discrimination of the rich and the poor, complexity of the educated and the illiterate." The situation is made worse because "people are scared of their faces and the fear of unknown," said NGOPL-2[161]. Such families are devastated in their communities and it is difficult for them to face others in the society.

D-2 told about a young teen girl who was sick for months and then diagnosed with HIV. Her brother "took her home and the next day he went missing from the home and he has not yet returned. He felt the shame . . ." [162]of facing the community. He was afraid of the deep offence that his neighbors would bring upon him.

The interviews made clear that children and their families go through stigma experiences in the community. Factors like fear, frequent sickness due to HIV, existing

[160] Interview notes of Pastor-A, on 17th December 2014.
[161] Interview notes of NGOPL-2, on 20th November 2014.

[162] Interview notes of Doctor-2, on 28th November 2014.

concept of shame in the culture and additional discrimination contribute to the intensity of stigma.

Experiencing Stigma in School

School is another place where children go through hard moments of HIV stigma. First of all, children live with their mothers, because they have already lost their fathers to HIV years before. C-A (Age: 17) grieves the death of his father and mentions, "I used to feel bad because my friend's dad used to visit our school and it was then I realized the absence of my dad in my home. I kept myself aloof, but later I just consoled myself."[163] The sense of loss of father or mother puts the child in a very stressful situation that may cause him or her to be aloof or withdrawn from others at school. Another reason for keeping oneself aloof as described by NGOPL-2 was "fear of being disclosed about being HIV positive." Speaking about a teen boy, NGOPL-2 says that, "he keeps himself aloof and away from friends." Fear of rejection and being discriminated is the main reason the children keep themselves aloof or withdrawn from friends in school and in their community.

Another closely related fear is that of losing friends at school. Disclosure or discovery of their HIV status often leads to loss of friendship. NGOPL-3 elaborates that children are "scared of losing friends in school . . . and so they are scared to open up with even their close friends." PAS-A spoke about a 12 year old boy who at school, used to be alone, felt aloof and experienced feelings of resentment and anger.[164] C-B (Age: 15) explains, "When we are with our friends, they talk about someone being infected with

[163] Interview notes of Child- A, on 22nd November 2014.
[164] Interview notes of Pastor- A, on 17th December 2014.

HIV, but they don't know that I am infected. So I get scared if they come to know about me, too."[165]

Children fear another situation, which is the time when they have to respond to teachers and friends about falling sick quite often. Frequent absence from school raises questions. P-C commented, "Teachers used to suspect that she is HIV-positive. My daughter falls sick quite often so the teachers and her friends used to wonder what is happening to her, why she feels sick? Even now they suspect she is HIV-positive but they don't ask her in open."[166] Children fall into mental distress because they are stigmatized and face the tough challenge of deciding how to interact with teachers and friends without disclosing their HIV-positive status. Thus in such situations they are pushed into staying away from friends at school and dread losing their friends as a result of their HIV-positive disclosure.

Children with HIV also have to bear the teasing or taunts (*galis*) by other children. Recalling some teasing among his friends in school, C-A (Age: 17) says, "Sometimes in our school now, children tease using bad words (*gali)* saying, '*kya tere ko AIDS hua hai kya* (Have you gotten AIDS?).' These comments make me scared, if my school friends come to know that I have HIV, what would happen? I don't get close to my friends; I don't go out with them."[167] Just the very use of the words HIV/AIDS frighten the children to death in schools. The friends of C-F (Age: 10) tease her by calling her a "sick

[165] Interview notes of Child-B, on 8th January 2015.

[166] Interview notes of Parent-C, on 4th February 2015.

[167] Interview notes of Child-A, on 22nd November 2014.

girl." She feels bad about this; however, she cannot help but go to play again with those same friends.

Apart from being teased and taunted by friends in school, children also experience discrimination by teachers at their schools. C-D (Age: 13) recalls an incident when she was made to sit on a different bench in her class. Her teacher warned other children, "Don't talk too much with her (*isse koi jyaada baath math karo*). " Her mother**,** P-D**,** narrates the difficulties she encountered while seeking admission for her daughter. After she had disclosed to the Principal about her daughters' HIV status, she was refused admission. But after a couple of attempts, with the assistance of a social worker, she got her daughter into that school. In another instance one of the schools in Andheri, which is one of the suburban areas of Mumbai, children remarked, "Don't use her comb, her mother is an HIV-positive lady."[168] Such practices of stigmatization lead to withdrawal and seclusion in school or even at homes. PAS-B sites an incident when the teacher, after finding the girl getting absent, asked her why she did not come. The girl told her teacher that her dad had been sick with HIV/AIDS and died. The teacher separated her from the other children in the class and asked her not to interact with them or even play with them. The child used to feel very guilty and ashamed of being discriminated or even set apart. She quit school.[169] In extreme cases when children experience stigma they drop out of the school and that impacts their future. These findings, that stigma still persists in educators

[168] Interview note of NGOPL-1, on 3rd December 2014.

[169] Interview notes of Pastor -B, on 14th January 2015.

at school confirm findings of a study conducted in Kwasulu-Natal, South Africa, I think you need to include a quote from the South Africa study.[170]

Another significant issue regarding fear of disclosure is when the teen children wish to have boyfriends or girlfriends. Young boys and girls living with HIV sometimes express their sexual desires toward one another, leading to some physical intimacy. P-A, D-1 and NGOPL-3 are in agreement that these young teens feel incapacitated in their relationships. In extreme cases, they lash out in frustration at home because of this fear. In one of the incidents mentioned by NGOPL-3, a young boy who is HIV-positive and felt lonely and did not have a girlfriend became addicted to alcohol and abused his mother for sex. The boy faced stigma outside the house, so his coping mechanism was to try sex on his mom. Such an extreme response is another outworking of the psychological impact of stigma in the life of this young person. Situations similar to the ones illustrated here verify the conclusion that children along with their parents experience stigma on many different levels. It is observed that they have suffered stigma in their extended families, at school and in their community.

The second research question discusses the different ways children infected and affected with HIV cope with stigma.

How Do the Children Infected and Affected with HIV Cope with the Stigma Encountered?

[170]Becky L. Genberg and others, "A Comparison of HIV/AIDS-Related Stigma in Four Countries: Negative Attitudes and Perceived Acts of Discrimination Towards People Living with HIV/AIDS," *Journal of Social Science* 68 (2009): 2279-2287.

During my interviews with children and parents I had to simplify and explain the word cope in Hindi and Marathi. So the simplified and paraphrased question as translated became, “How do the children infected and affected with HIV adjust or overcome the problem of stigma?” Children and parents helped me understand the answer to this question through sharing incidents that marked their coping mechanism. Pastors, doctors and NGO Project Leaders had their own different views while I interviewed them. This section will discuss the different coping strategies of children, whether by coping positively or negatively.

Coping Negatively with the Stigma Encountered

Children and families living with HIV have many emotional, physical and psychological hurts attached to the issue of stigma. While I was doing the “family constellation” activity many children did not include the father figure on their board. They did not include the figure of their father on the board. When asked about the picture they had made, they said that they missed the father figure in their family. This activity stimulated their memory of the past, capturing their times with their complete families.

Child-A (Age: 17) took almost forty minutes to construct the family model on the board. He used attractive colors to make the figures of each member of his family. Lost in total silence, he put all his feelings into the making the family model, which had three figures, depicting his mother, father and himself. I was confused with this figure because I knew that his father had committed suicide years back when he was still a small boy. However, after several minutes of studying the family he had created, I was shocked as I watched him grasp the father figure and crumple it, with sadness written on his face and tears welling up in his eyes. As he began to explain, C-A (Age: 17) mentioned, “When I

was making the family model, I remember all the past days, when we used to be happy, my dad used to love me so much. When I see my uncle and aunty, children playing with them, it hurts me to know that I do not have dad to play with."[171] The absence of the father figure significantly affects the coping mechanism of a child. For the children in my study, the absence of a play companion in a father hampers their coping mechanism. Further, C-A explained the poverty status of his family and mentioned that he was not privileged to go to school because his dad had been sick, and had now died. He was gone and his mother had nowhere to go. The child was deprived from school for lack of a father figure who could earn in the family. Being unable to attend school, set the stage for him to develop negative coping strategies.

D-1 stated that in the absence of the father, most of the time children do not cope well. Quite often single mothers who play the role of both parents care for the children. In this case, the mother being the sole breadwinner is out at her job most of the day or sometimes even multiple days. Without the presence of either father or mother many children turn to negative coping strategies. In the pursuit of companionship, they fall prey to wrong friendships and as a result find their identity among bad companions. Many children begin to get in with gangsters (*gundagiris*), may dabble in substance abuse, and eventually fall into a cycle of bondage.

NGOPL-3, who is a consultant for HIV forum projects, indicated that single parenting poses a great challenge for children with HIV to deal positively with stigma. In her experience, she had not seen children coping any time. Since most of the mothers are the only breadwinners, they go work leaving their children all alone at home. And so the

[171] Interview notes of Child-A, on 22nd November 2014.

mothers are kept away from the truth that, in their absence, their children are being ill treated by the society.[172] Children do not understand the reason why they are discriminated by their friends. One of the reasons children cannot cope is because their parents must work to support the family and therefore have little time to spend with their children. And so the children find a gap in communication between them and their parents.

From the above paragraphs, it is understood that it is difficult for the children to cope with the stigma issues they face in the society. Most of the parents also agree that it is very hard for children to cope. In her emotional distress P-C states , "Children are not able to cope. We adults know what the whole problem is, but with children, it is very hard for them to understand the disease or even why we make them take their own medicines." The situation being all the more difficult, she continues, "Even in schools she is not able to participate actively in sports or any physical activities, my daughter keeps wondering why she gets sick often and asks, 'Why do I fall sick quite often (*kyon ghaddi ghaddi bimar padti hoon*)?' " The question remains unanswered in the hearts of children. Children hesitate to participate in school activities because they feel lethargic due to the fact that their health is compromised. In another instance P-D affirms in her tears that children cannot cope "My daughter keeps asking me how I got this HIV …. It is my mistake not hers**.** I can understand the whole situation, but it is hard for children to know all these things . . . why and how."[173] The uncertainty of the whole issue of HIV leaves the children in suspension, making it difficult for them to cope. NGOPL-1 and NGOPL-2 mentioned that they were not aware of many children coping well with the issue of HIV

[172]Interview notes of NGOPL-3, on 23rd February 2015.
[173]Interview notes of Parent-D, on 8th January 2015.

stigma in school or community unless the assistance of a social worker or church is offered to them.

To control the viral load in the body system, people with HIV are required to take their medicines at the prescribed times. When children are asked to take medicine without knowing the reason for it, they do not understand the importance of the medication, and it raises questions. What is wrong? Why do they need the medicine? Even more problematic, when they are told by their parents not to disclose that they are sick, this raises questions and fears. But with no explanations and opportunity for processing the reality, children are left with their questions and fears, and no assistance for coping.

Coping Positively with the Stigma Encountered

As I conducted my interviews, I began to realize that not many of the parents or they key informants spoke of their children coping positively; rather the parents hoped for something or someone to help them cope positively.

Although in many cases children were not able to cope well, my interviews also highlighted a few cases where the children have made attempts to cope positively. In the strategy of self-defense, C-A (Age: 17) argued, "If anyone knows in our neighborhood, it is better to move to another place and start a new life…. In our case everyone knew that our family was living with HIV. So we had to move to a new place. And if we don't have much capacity to move to a new place . . . then it is better to face the situation."[174] He comments further, "Let the dogs bark (*Kutta bhaukta hai to bhaukne do*) . . . so we can live our life." This is a cultural saying that equates unwanted taunts of people to the lazy

[174] Interview notes of Child-A, on 22nd November 2014.

bark of a dog. “People look at us as a criminal. They just know that once a person has HIV, he has to die. People will not understand the entire situation.” The child figured out two strategies: moving out of the neighborhood if that is affordable or let go**,** live in the same area**,** and accept situations beyond the family’s control. Another example of a let go strategy in coping positively was illustrated by C-D (Age: 13). She said, “We should not worry more . . . or listen to others . . . because it is not our mistake. *Jo hai to hai* (what is there is there)… We cannot do anything…We just have to be bold and strong.” With little resentment in her tone, she is hoping to cope positively. The view is shared by P-A, “We have to be strong . . . accept it and take medicines.” [175]

Among the younger children who heard me narrate the story of Raju and Rani, C-E (age 11) responded, “They (children) could study in some good schools…. Raju and Rani’s mother could approach some NGOs to work and earn for their family.” C-C (Age: 12), not very sure of herself, expresses, “They (Raju and Rani) need to seek someone’s help to live . . . otherwise it will be hard for them.” This child had discovered that by relating her story to someone and asking for help she could cope with the issue of HIV-related stigma. P-B asserts that with the support of someone to care for them, “We can cope with the problem of HIV . . . we can be a parent to the children orphaned by HIV.”[176] By parenting other’s children P-B asserts that she could help them cope.

Both NGOPL-1 and 2 suggested that children could cope with HIV stigma if the church would support and care for them. P-E talks about some NGOs that initiated help for children and families in coping by providing some monetary support for them. In

[175]Interview notes of Parent- A, on 22nd November 2014.

[176] Interview notes of Parent-B, on 8th January 2015.

some cases churches and NGOs have been helpful in aiding them to cope with the entire issue of stigma in the lives of families and children with HIV.

The third research question focuses on the impact of the parent's stigma experience on children.

How Does the Parent's Experience of HIV Stigma Impact the Children's Experience of Stigma and Coping?

Parents and children are inseparable people who journey together with their ups and downs together in the journey of HIV/AIDS. We have observed that parents are able to cope with the whole issue of stigma only with the support system that they receive from community, church or NGOs. Children, however, find it more difficult to cope or rather, most of the times they do not cope with the whole issue of stigma. Their incapacity to adjust is reflected in various domains of their lives. Further, the stigma experience of the parents does impact their children in various ways: psychosocial behavior, academic opportunities, health, and spirituality.

With the onset and the increased accessibility to ART, there is a decline in the number of HIV patients, but the threat that HIV is posing for children**,** especially adolescents**,** remains significant. HIV-positive children with any chronic illness do suffer tremendous problems, whether physical, emotional, psychosocial or spiritual. The most important aspect that makes HIV/AIDS more severe than other illnesses is the stigma attached to it. This is what causes the parents who go through the stigma experience in their own lives to hide this issue from their children**.** It is kept as a secret or presented in a status of disguise**,** projecting guilt and shame. Families living with HIV/AIDS, for this reason socially withdraw themselves from society or have been isolated by the family members. Therefore the parents' experience of stigma in the journey of HIV/AIDS has

deeply impacted the children. This next section discusses the psychosocial, physical, and spiritual impact of stigma on children's lives.

Psychosocial Impact of Stigma in the Lives of Children

Children infected and affected with HIV/AIDS are experiencing the psychosocial impact of their own stigma experience as well as that of their parents. Already the families are cut off from their extended family members. This breeds a sense of anger in the hearts of the parents who suffer stigma themselves. This in turn is subconsciously infused in the minds of children, especially the young adolescents. C-A (Age: 17) mentioned, "When a person discriminates against me, I used to think that they should also get HIV. I get angry**,** frustrated."[177] Children may react to their stigma experience with a revengeful spirit.

When asked how does a person feel when he or she is infected, C-D (Age: 13), responded that she feels angry at the people who discriminate against her or her mother.[178] Anger becomes an expression of defense against discrimination and as a result children start cursing themselves**,** asking why people behave negatively toward them. They not only curse themselves, but as children capable of understanding the bigger picture, they start blaming their parents**.** In the case of C-D, it is her mother who is blamed.

P-A described that her son always blames her for having infected him with HIV. He says, "His dad was good. . . . You might have gone to men and so you got it. And now

[177] Interview notes of Child-A, on 22nd November 2014.

[178] Interview notes of Child-D, on 8th January 2015.

I have it, my son gets emotionally upset, then he blames me."[179] The mother cried and further mentioned that she would just want to give up when her son speaks so harshly to her. Being so incapacitated with social isolation from outside and within, children tend to subdue their anger against those who discriminate and yet retaliate towards those who love them.

Anger greatly impacts the children of adolescent age and results in self-withdrawal. When I spoke to the HIV project leader of the Dayanand Foundation about interviewing C-B (Age: 15) I was told that this teen boy keeps himself aloof and does not even want to open up with any of his family members. Appearing to be just like twelve years old boy, he was small for his age. During the interview he spoke in a very frail voice. This behavior was another form of subdued anger. Also when I observed Child-C, 13 years old, at a gathering during Christmas and at other times, she remained secluded from other children at party time. She appeared undernourished and always was seen sticking to her mother. Withdrawal is a sign of impact on the children. The mother of an eleven-year-old complained, "My son does not talk much. I do not know why. Maybe he

knows that he has some sickness." I understand that fear of discovery followed by the very act of discrimination causes self-withdrawal.

In his drawing C-E (Age: 11) included himself, his parents and his older brother. Since frequently C-E had to be taken to the hospital for HIV treatment, his parents were not able to give attention to his elder brother, so they put him in a hostel. C-E explained

[179] Interview notes of Parent-A, on 22nd November 2014.

that he had not drawn his hand holding the elder brother's because he was away in the hostel and felt that he missed him. The older brother was affected by his younger brother's HIV infection; he suffered separation from the family.

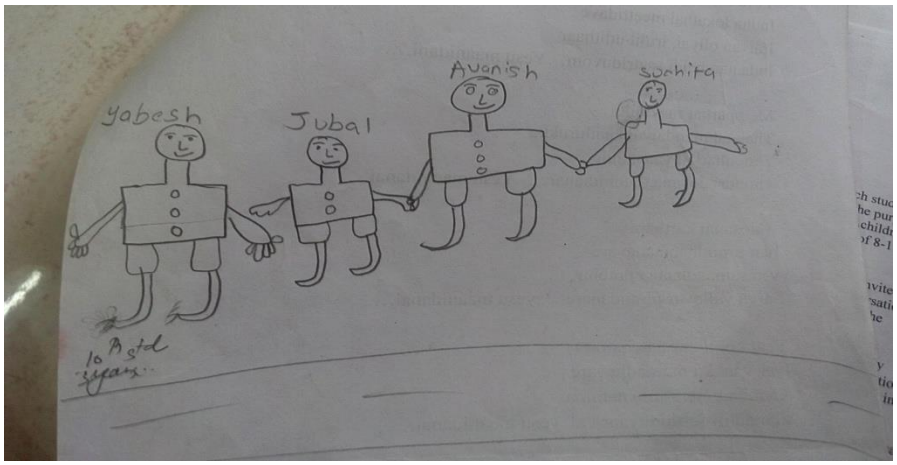

Figure 7: Drawing of C-E (Age: 11)

The following is the analysis of Dr. Aileen Grace Prochina-Mamahit, a clinical psychologist, on the drawing of C-E (Age: 11):

> His drawings show indications of poor self-concept with feelings of inferiority and uncertainty about his future. It also indicates that there is a strong need for security. There are indications of presence of anxiety, feelings of emptiness, possible emotional disturbance or depression, helplessness and hopeless about the future. The boy appears to cope by trying to distance himself from others and by trying to suppress his emotions and feelings. His drawings also indicate possible mental retardation or possible organic conditions. It is strongly recommended that the child go through psychological evaluation.[180]

On the one hand the parents' stigma experience impacts children in many aspects and also they themselves experience stigma and discrimination. It is a kind of double layer of stigma impact on children.

[180] Aileen Grace Prochina-Mamahit, "Analysis of Drawings," 21st June 2016.

Many parents going through many ramifications of stigma do not attempt to disclose their HIV status to their children. NGOPL-3 confesses that stigma issues related to HIV/AIDS still continue to exist. Parents often do not attempt HIV disclosure to children. Children take medicines but they are not aware why they are taking them.[181] In school when children take medicines, there are teachers who are curious to know the names of the medicines and thus require the students to write out the names. Such incidences have created a threatening experience not only for parents, but also for their children. The disclosure of HIV in schools is very sensitive and so it creates fear in the lives of children with HIV.

In my interview with D-3, who cares for families with HIV/AIDS in a hospital run by a Trust**,** she mentioned, "When parents are treated badly in their community, or in their extended family**,** the children go through a lot of hurt and feel disowned. There is a family in our neighborhood where the father was HIV infected and died after a few years of suffering**.** The mother was also suffering with HIV. The child with HIV was told not to talk much to other family relatives and not to have many friends or they would discover his problem."[182] This case described by D-3 is supported by Jose Catalan's observation that HIV not only affects the physical health of the person but also has adverse effect on psychological and social relationships.[183] It not only affected the adults but also has adverse effects on children.

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[181] Interview notes of NGOPL-3, on 23rd February 2015.

[182] Interview notes of Doctor-3, on 20th November 2014.

[183]Jose Catalan, "Psychological Problem in People with HIV Infection," *Mental Health and HIV Infection, Psychological Psychiatric Aspects* (London: University College Press, 1999), 21-22.

The parents protected their children from being discovered as HIV-positive persons. Also in the disclosure of HIV to their children, the parents manifest a sense of shame and guilt as to "how to show our face in our society or what others will think of our family if they come to know of us."[184] Therefore, the conspiracy of silence is seen in the way children come to understand the whole issue of HIV/AIDS. With all that the parents go through, they have unconsciously birthed a sense of fear, guilt and shame in the hearts of children. It is observed that a great emotional scar is left unprocessed in the lives of children.

The young children go through emotions like anger, denial, fear, guilt and shame, and they have found no place or no one with whom they can vent their feelings. Since HIV/AIDS is mostly considered something to do with sexuality, the aspect of disclosure becomes even more challenging. Such bottled up feelings have an adverse impact on young teens. In one of the interviews P-A surprised me when she said, "My son gets mad sometimes in night, throws me down and beats me very bad . . . [and] uses abusive words on me."[185] As I observed this young teen's behavior, I sensed that in some cases the unprocessed feelings of children are taken out on their parents and vice versa.

Withdrawal is another form of psychological impact observed on children. C-B (Age: 15): "There is a fear that they will talk bad (*bura*) about that child. He may lose good friends. Some friends will tease that boy that he is sick always."[186] He had heard from a staff in a hospital that HIV drains strength out of one's body and thus makes a

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[184] Interview notes of NGOPL-2, on 20th November 2014.

[185] Interview notes of Parent-A, on 22nd November 2014.

[186] Interview notes of Child- B, on 8th January 2015.

person feel sick most of the time. Again, falling sick is an impact of what the child goes through because of the talk by his friends. Hearing someone talk about their sickness affects children's mental health.

P-D**,** a widow**,** narrated that when her in-laws learned of her husband's HIV status, they did not talk to her . . . and even stopped talking to her children. With an overwhelming grief, she said, "My daughter has HIV because of me (*laga ki mere vajai se meri beti ko bhi HIV ho gaye*)."[187] In fact, the daughter had contracted HIV from the mother during her birth. The family members not only stigmatize the survivors but also by their reactions create a sense of guilt in to those living with HIV. This stigma experience of the mother affected the mental well being of her children.

The reality of living with HIV affects the sexuality of young teenagers, and even young children. In my interview with D-1, she mentioned a teen boy who demanded to have sex with his mom.[188] Not only did he become violent, but he also inflicted sexual violence. NGOPL-3 shared that, after their parent's death, children with HIV are quite often left with their relatives or some extended family members. Sometimes extended family members, who are the caregivers of the child, beat them on their private parts and demand sex from them.[189] P-F who is a grandmother of Child-F grieves to say that her youngest son**,** who is an alcoholic**,** tries to have sex with her eleven-year-old granddaughter in the night.[190] Children have been victims of all sorts of violence even within their families.

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[187] Interview notes of Parent- D, on 8th January 2015.

[188] Interview notes of Doctor-1, on 3rd December 2014.

[189] Interview notes of NGOPL-3, on 23rd February 2015.

[190] Interview notes of Parent-F, on 30th December 2014.

Another impact of stigmatized parents on children is seen when children behave indifferently towards their parents. PAS-B shared about a family where the children disowned the mother when they came to know from the others in community that their father had died of HIV. He further mentioned, "They maintained physical distance from their mom. The mother was broken because of her experience of discrimination by her own children."[191]

The most deeply hurtful psychological condition for many HIV-positive children occurs when they are semi-orphaned or orphaned. They miss their mother and father. While working on the "family constellation" activity I observed silence and even saw tears in the eyes of children. I had given each child some clay with which they were to mold various shapes. They were asked to create their family picture using the clay model on the cardboard they were given. When asked if anyone was missing in their "family constellation," most of the children mentioned that it hurts to know they do not have their father. During the "family constellation" time, C-A (Age: 17) mentioned, "While making the model, I miss my dad (cries)…. I wish I also had my dad to visit my school. My friends brag about their dads . . . but I feel like crying."[192]

A similar feeling was expressed by C-D (Age: 13),[193] while she worked on her "family constellation," her eyes totally welled up in tears and she spoke in a husky voice, "I have not known my dad. . . . My mom says that he passed away when I was just a little baby." The deep hurt of not having a father in the family was obvious in the eyes of the

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[191] Interview notes of Pastor-B, on 14th January 2015.

[192] Interview notes of Child -A, on 22nd Nov 2014**.**

[193] Interview notes of Child-D, on 8th January 2015**.**

child I interviewed. While child C-F (Age: 11) was drawing, I thought she was imagining her family with her mother, father and little brother. Being aware of the fact that she was an orphan, this drawing was raising many questions in my mind. After she took almost 30-40 minutes to make the drawing and color it, she was lost into deep thought and was silently staring at the pictures. At this juncture, I asked C-F to explain her drawing to me. Pointing at the figures, she said that she had drawn her grandma and grandpa and that she was close to her grandma. The reason that she had drawn herself near her grandma's figure was because she is close to her. She mentioned that she misses her parents so much (she cried and wiped her tears with the dirty frock that she wore). Then she continued her explanation about the other figures in her drawing. The little boy between the two adult figures is her little cousin. He is loved more because he is a little boy, she told me. In reality, the little boy in the drawing was the little three month old baby on the cotton sling cloth in her home that hung from the rod on the ceiling. It was interesting to see that C-F had not shown her two uncles and her aunty in the drawing, although they lived together with her and her grandparents in the small house that was just 12 feet by 12 feet in size. C-F (Age: 11) pointed to her drawing, which had no figure of dad or mom, but her grandparents, and said, "I miss my mom and dad. Figure 8 below shows the drawing of C-F (Age 11).

Figure 8: Drawing of C-F (Age: 11)

C-F says, "My mom and dad died of the same disease as I have and I lost my elder sister to this disease. I was very small when I lost my parents. I have not even seen them."[194] This child, having lost both parents and who was now being cared for by her grandparents, felt very devastated. In all these psychosocial aspects, children became resentful and different in their behavior towards their family as well as to others outside the family circle. Mamahit analyzed her drawings in this fashion:

> Her drawings indicate strong feelings of insecurity. There is also indication of feelings of helplessness and inadequacy that seem to adversely affect her desire to strive and set goals for herself. These appear to increase her feelings of dependency on others. Her drawing also shows desire for interpersonal interactions particularly with people who can show her affection and provide her with assistance or help.[195]

In another case of a child with Tuberculosis, the mother**,** P-E**,** was worried and she said, "When he got TB, I was so nervous. Sometimes I think my son should not have

[194] Interview notes of Child-F, on 30th December 2014.

[195] Mamahit, "Analysis of Drawings."

been infected with HIV." The painful experience and feelings that the mother has gone through is subconsciously passed on to the child in his or her journey.

Impact of Stigma on the Academic Life of Children

The consequence of HIV related stigma is wide ranging. In addition to impacting all aspects of life, including the health ailments that children suffer, a considerable degree of changes happens in their academic life. Their weakened immune system leads to multiple infections that negatively affect their body and their wellbeing. P-B, in her interview**,** mentioned about her daughter's inability to concentrate on her studies at school. She eats her school food and then regurgitates the food quite often during break time. With no one to care for her at school, she quite often chooses to be absent from school.[196] Some children escape school and studies to avoid discrimination at school. Speaking about her son, P-A mentioned "He skips classes in his school quite often . . . he kept missing his classes in between school days (*beech beech me nahi jaata*), so he failed in his class now."[197] Older children used skipping or missing classes as a means to escape taunts and teasing at school. This affected their studies in great measure.

Sometimes children fear going to school at such times. When her teachers asked for a reason for frequent leave taken, Child-C hesitated to say that she was sick. According to her mother, Parent-C, the teachers suspected her of suffering with some serious disease**:** "They also ask children for blood test sometimes, so my daughter skips school on those days too."[198] The suspicious attitudes of teachers in the school threatened

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[196] Interview notes of Parent-B, on 8th January 2015.

[197] Interview notes of Parent-A, on 22nd November 2014.

[198] Interview notes of Parent-C, on 4th February 2015.

other HIV-positive children, as well, and negatively affected their studies. When interviewed about her school, C-D said, "Sometimes I don't like to study in that school because of what my teacher did to me . . . she made me sit separate, away from my friends."[199] The teachers' attitudes not only broke the spirit of children with HIV, but also triggered the negative attitude of their friends at school toward them.

In my interview with PAS-B, he spoke of a girl who was made to sit apart from her classmates because her father had died of HIV/AIDS. The teacher suspected the girl to be an HIV patient, too. The child felt guilty for her father's death and felt ashamed of being discriminated against and therefore quit the school. In general, HIV-positive children find ways to adapt by ventilating their feelings about the discrimination they experience. In this case, that was accomplished by skipping classes**.** This of course negatively affected their studies in considerable ways.

In an extreme case, I was shocked to hear from PAS-A about a family who pulled out their child from school, because he was HIV-positive. The parents expected the child to die very soon because of his illness**,** and his deteriorating health spoke of his degrading health condition**,** as well. They felt that it was a waste to spend money on a child who would die soon anyway.[200] Instead they would save that money for other children. The parents, even though they were the caretakers, reacted in a very discriminatory way toward their own child.

Impact of Stigma on the Health of the Children

[199] Interview notes of Child-D, on 8th January 2015.

[200] Interview notes of Pastor-A, on 17th December 2014.

Across several years of ministry with families and children with HIV, I have heard stories of parents who speak of their experience of stigma at various levels. Being shunned by family members, peer pressure from the community and ill-treatment at the healthcare settings and work places are the stigma indicators. It is interesting to see how the sphere of stigma experiences widens from family to neighborhood, workplace and even into heath care centers.

Most of my study respondents live in very congested communities where one can easily contract illnesses from others in the family or the community. For many of their families, the atmosphere (or environment) in their home is not healthy. I had to travel one and half hours to interview C-A (Age: 17) who resides in a slum rehabilitated house. The house was too small I had to interview him in his kitchen which is just large enough for both of us to sit on the floor. Inability to afford a new house in a better place kept the family in an unhealthy atmosphere. With all the drainage dirt around the building, the family lives in unhygienic place. The mother and child sometimes are confined to their house for weeks due to unpleasant behavior from their neighbors. The way the neighbors taunt and look down upon them kept the family indoors sometimes. Such confinement not only affects their mental wellbeing, but also their physical health to a great degree. C-A mentioned that the family had no other choice, but to stay in the same locality and bear the guilt and shame.[201]

The Impact of Stigma on the Spiritual Lives of Children

[201] Interview notes of Parent-A, on 22nd November 2014.

In my interviews with mothers, many of them shared about faith in God and in the church. Mainly because of the attention and care they have received from the **c**hurch and faith community, some of the mothers have begun to place their trust in God. Others, as they deal with their pain and suffering**,** are left with questions regarding God. P-D**,** out of her own guilt of suffering HIV stigma, mentioned, "I feel guilty for giving my HIV to my daughter . . . why has God done this cruel thing to my daughter? It is okay for me to suffer in this society, but why my child?"[202] But through the love and care of the church, some of the mothers and their families have found God and a deeper meaning of life. Questions about God that arise out of the sense of guilt and shame the parents are experiencing are to be expected. If no one is there to help the parents find positive answers to these questions, this negative attitude and the guilt is learned by children**,** too. Therefore it is significant to understand that the church has to take measures to help these mothers process their guilt in order to eventually save the children from negative impact.

In my interview with PAS-C, he spoke about a child of a widow mother living with HIV. The mother has gone through great miseries and struggles. And her son, who has seen his mother suffering, is not open a relationship with God. His persistent questions are, "Why has God done this to my mother? If God loves us, then he should not have allowed my mother to suffer."[203] He refuses to even talk much to pastors or other church people. The stigma and suffering of his mother with HIV has had a negative impact on this child's spirituality.

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[202] Interview notes of Parent -D, on 8th January 2015.

[203] Interview notes of Pastor-C, on 6th February 2015.

The fourth research questions focuses on the ways how children and parents infected and affected by HIV perceive the church as an agent of holistic nurture.

How Do Children and Parents Infected and Affected by HIV/AIDS Perceive the Church as an Agent of Holistic Nurture?

One of the callings of the Church in today's context is the ministry of healing driven by compassion. In a study conducted in Africa, Riva Miller and Derval Murray found out that "Church leaders can be influential in guiding members about matters of HIV testing, disclosure of a diagnosis to a partner and accepting medication. Many religious communities can provide the comfort and support that could normally be available from extended family.[204] Preaching the good news to the poor is the prime goal of the church**,** preaching not only in words but in acts of mercy and justice. However, the inclination to the social expression of the gospel is sometimes overlooked. Since the families of this study attend the meeting at Free Methodist Church at Andheri on the third Thursday of every month, it is essential to understand their perspectives on the Church. This section of the chapter analyzes what image the church has created in the lives of families infected and affected by HIV.

The Church as a Home of Love and Acceptance

In their journey with HIV, affected families look for hope, love and acceptance. In my interview with C-A (Age: 17), he realized that the church is like his family. He said, "They helped us to move to a new place." He also pointed out that the church must try to know the problems of those living with HIV, so there would be a wider platform for them

[204]Riva Miller and Derval Murray, "The Impact of HIV Illness on Parents and Children, with Particular Reference to African Families," *Journal of Family Therapy* 21, no. 3 (December 2002): 292.

to speak out and discuss their issues in the church.[205] In the heart of growing teens like C-A (Age: 17), as they walk through the experience of stigma themselves along with their parents, they expect the church to identify their problems and help them by organizing programs in which they can discuss their problems openly with those who understand. Children in this study also mentioned that at church they had friends to play with, and they like the church because people talk to them nicely.[206] At school and in the neighborhood, they might face stigma, but it was interesting to know from children that they had some friends at church who were walking the same journey that they were walking. These friendships were possible when they came together every third Thursday for the Care and Share meeting. This is a gathering for families living with HIV. These families gather at Andheri Free Methodist Church. This is the time for children with similar problems to come together so they can have an opportunity to build friendships with each other. A similar expectation was shared by P-C who mentioned, "I feel church must be a family, so the pastor must motivate others to mingle with us and have fellowship with us."[207] Stephen Covey also believes that church leaders should be preparing the platform for the acceptance of people who are marginalized.[208]Although church is Care and Share meetings, held at a church, provide a place where people with HIV feel like a family, they also wish the church members could be motivated to

[205] Interview notes, Child-A, on 22nd November 2014.

[206] Interview notes of C-E and C-F, on 27th and 30th December 2014.

[207] Interview notes of Parent-C, on 4th February 2015.

[208]Stephen R. Covey, *The Leader in Me* (New York: Free Press, 2008), 41.

welcome their families into more adequate fellowship with members of the broader congregation.

Nevertheless a little different perspective was also heard from the parents. In their interviews, one of the parents, P-A**,** expressed, "The churches do treat us well, because they do not know about our status. So we better take care of ourselves. Not hugging anyone . . . or touching babies…who are newborn. If the baby falls sick, they might think that the baby fell sick because I touched the baby. I don't kiss anyone, just give flying kisses."[209] This shows that they live with the fear of being stigmatized if the church discovers their HIV status. Taking some precautionary measures such as being careful in hugging anyone or even refraining from touching babies are considered to be wise even in churches. P-B brought to my notice that she and her family were treated well by her pastor in the early stages of her journey with HIV, but after a few years**,** the church neglected the ministry towards families with HIV[210] thus these families had nowhere to go for hope and help. In fact she also mentioned that the pastor taunted her about her HIV status. In situations such as this the families feel disowned and live without anyone to care for them. This suggests that the pastor might have lost the passion for ministry to people with HIV and had deteriorated into a taunting type of person. It was a kind of betrayal of trust on the part of the church and the pastor.

In analyzing the concept of love and acceptance, most of them expressed that the church offered warmth, but they were concerned about the possible disclosure of their HIV status. The fear of being discriminated against still possessed their lives.

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[209] Interview notes of Parent-A, on 22nd November 2014.

[210] Interview notes of Parent-B, on 8th January 2015.

The Church as a Means of Healing

The Care and Share ministry of Danyanand Foundation is a wing of the Free Methodist Church that caters to the medical needs of families living with HIV. Ministering to the spiritual needs of children and families with HIV is essential to understanding their longings for inner healing in their bodies and spirits.

When children get to play with friends at church, they experience this healing. One of the children who keeps herself aloof is C-C (Age: 12). Her father is an alcoholic and rarely shows any love towards his children and family. So the child longs for love which could heal her hurts and feelings. She mentioned that she is happy to receive gifts during Christmas time. She also plays with friends when she comes to church for the Care and Share meeting.[211] Playing with friends and having fun brings healing to a child who is going through stigma at her school and even in her own family. Similarly P-D feels "so good and relaxed when she comes for meetings at the Free Methodist Church."[212] She gets to talk to people and has opportunity to discuss her stress and feels healed. Parents as well as children experience healing when they find time and space to speak with the circle of their friends about their journey of HIV stigma.

C-D (Age: 13), in her interview expressed her desire for the church to extend their ministries to families like hers. "The church must come and be with people living with HIV in times of need . . . and help them stand against the negative attitude of people."[213]

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[211] Interview notes of Child-C, on 4th February 2015.

[212]Interview notes of Parent-D, on 8th January 2015.

[213] Interview notes of Child-D, on 8th January 2015.

Having experienced stigma at school, she realizes that fighting all alone against stigma is very challenging. Affirming the same expectation, C-E (Age: 11) commented that not many of the church people come to their home**.** She desires that church members visit her family.[214] This will give them hope to heal and live.[215] Sadly this is not happening as much as it should be. This is seen as a failure on the part of the organizations that work among families living with HIV.

C-F (Age: 10), who is an orphan living with her grandparents**,** wishes that the pastor or the members of the church would also visit her family.[216] She longs to have friends from her church. Her grandmother being a sick lady is helpless at home. Most of the time she is on her bed, so this child hopes that the church will come to her home to pray and provide support. In another interview, the sick mother P-A mentioned that she would be very grateful if the church could take care of the children who are suffering with HIV physically.[217] Since the mothers themselves are sick and exhausted they look to the church to help their children who are sick**,** too.

Children and parents, who live with HIV, spoke about church as a source of healing they would receive if the pastors or the members would visit their homes to help stand against the stigma they face.

The Church as a Means of Spiritual Nurture

[214] Interview notes of Child-E, on 27th December 2014.

[215] Interview notes of Parent-E, on 27th December 2014.

[216] Interview notes of Child-F, on 30th December 2014.

[217] Interview notes of Parent-A, on 22nd November 2014.

Churches may provide medical and social resources, emotional and physical wellbeing. However, the higher calling of the church is to offer spiritual healing to children and families infected and affected with HIV.

Most of the children and parents in the study do not belong to the Christian faith. As they attend the Christian gathering at Andheri Free Methodist Church once a month, they experience the impact of spiritual nurture through prayer gatherings. Those who attend these gatherings, who believe in other religions, have never denied an offer of prayer. Children and families realize the importance of prayer as a means to invoke God's blessings upon them. This finding about spiritual nurture affirms what was discussed by Dan Brewster that church must strike a balance between caring for the physical and the spiritual needs of a person, thus aiming towards holistic nurture.[218]When C-B (Age: 15) experienced stigma as a result of his mother losing her job, he urged the church members to visit his home and pray for his family.[219] C-B believed he and his mother would receive spiritual nurture when a pastor or church members at their home and in church offered prayer.

While talking to the younger children of eight to ten years, I narrated the story of Raju and Rani to help them understand their experience of stigma. When asked, "What can the church do for children like Raju and Rani?" C-C (Age: 12) responded that apart from financial helps and supports, "the church people could first pray for children like Raju and Rani."[220] The younger children understood prayer as a means to get things from

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[218]Dan Brewster, Child, Church and Mission: *Resource Book for Christian Child Development Workers* (Makati City, Philippines: Church Strengthening Ministry, Inc., 2005), 41.

[219] Interview notes of Child-B, on 8th January 2015.

[220] Interview notes of Child- C, on 4th February 2015.

God. C-E (Age: 11) also mentioned that the church people must pray for people like us. They must support them. The child could identify himself with the story of Raju and Rani. The only means of spiritual nurture for these was through prayer that could be offered for them by the pastors and the church people. In fact this is the only spiritual nurture they have received from the church, and they value the prayers offered by God's people.

Widow mother P-A, who is very thin in stature and no longer has strength to work, lives on the little money that is provided by her local church and her child's support that she receives from the Dayanand Foundation. She mentioned, "The church has to pray…we have no other place to go . . . other than prayer and coming here to the church. My hope is only in God. . . . I don't know who will take care of my son after I am gone. I leave it to God. I do not know how to read the Bible . . . but I like to sing when I come to church for meeting."[221] Being a non-literate person her only hope is in God and so she expects that the church must make frequent visits to her home and also provide spiritual nurture to her only son who is now a growing teen boy. Having lost her husband at a young age, she struggles to make ends meet; however, she is quite content with what she receives from the NGO.

In deep exhaustion of spirit, the old grandmother who is the caretaker of C- F (Age: 10) pleaded for me to visit their home more often. She mentioned, "Pray for us more, and help us live. There may be so many like my son who have died, or are dying like us every day. Visit our homes**,** we feel good if there is someone like you visiting us, sit with us a while and talk to us, you people are like God to us. . . . We feel Jesus at our

[221] Interview notes of Parent-A, on 22nd November 2015.

home today."[222] Her earnest desire for someone to visit her home and pray for her and her grandchild was apparent.

As I continued with my interviews to find out the perspective on the church from children and parents, P-E who attends the church that I and my husband previously pastored, stated with great contentment, "They asked us to put our burden on God. So we live our lives for today."[223] She lives in a rented house, just one small room which is her bedroom, kitchen, living room and everything. However**,** she is happy to be coming to church with her son who is also HIV positive. She is very worried about her son because of his deteriorating health condition.

All of the children and parents see the church as a body that can offer them spiritual nurture through prayers, reading the Bible to them and visiting them during their lonely hours of sickness and stigma.

The Church as a Monetary-Supporting Body

To live a healthy life style with positive thinking and to be able to support their children, the families living with HIV require some economic support from funding agencies. Some support care systems are set up by the NGOs to cater to the financial needs of families going through stigma at work places.

Government supported clinical care and medical support is given at the Free Methodist Church where one doctor comes to offer HIV-positive individuals medicines and to treat other infectious diseases. Most of the medicines are distributed to them free of charge, but some of the basic expenses for education and children's nutrition are met

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[222] Interview notes of Parent-F, on 27th December 2014.

[223] Interview notes of Parent-D, on 27th December2014.

by the support that is received from Dayanand Foundation. C-E (Age: 11)**,** while listening to the story of Raju and Rani**,** said, "Raju and Rani may not have money for their food or school. The church must help such children to study . . . or put them in a hostel."[224] Despite the help received from other NGOs this young child realized that the church is the body that could offer monetary support to children without any help and hope. Realizing the fact that there are many children living with HIV, C-C (Age: 11) stated that, "The church must be able to take care of their education and help them with their fees to pay for school."[225] Affirming what Child C said, P-D revealed her story that the support offered by the church is not even sufficient for her bread and butter, so she has to work in some houses as cook to support her children's fees and other house expenses. She sees education as a powerful weapon to stand against the stigma her daughter has been facing in her school.

The children and the mothers who responded were on ART, which is a high dose of medicine for HIV. To build stronger immunity against other infectious diseases and to fight the side effects of the medicine, patients are required to be on a nutritious diet. Many times, with the little support they receive, the families are left with no money to get their medicines other than ART and nutritious food, so C-D and C-F mentioned the church must take care of children with HIV and provide them with good food and medicines.[226] The church would, thus, help save children from other infections and help them create better immunity.

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[224] Interview notes of Child-E, on 27th December 2014.

[225] Interview notes of Child-C, on 4th February 2015.

[226] Interview notes of Child-D and Child-F, on 8th January 2015 ~~and~~ and 30th December 2014.

P-C offered an important insight. She mentioned, "My church supported me so much. Even now, my pastor comes to visit me. She has always taken care of me. But since I bought this little room, my pastor and some of the church people are offended at me, afraid that I will ask them money for further help (*unko laga ki, mai paisa poochoongi*)."[227] Such fear was also experienced by C-A (Age: 17) who thought that the church would think his family needed money. There seems to be a fear of being viewed by the church as simply a dependent.

In my findings for research question four, I discovered that the younger children saw the church as a comfortable place to play with friends and older children found church as a body of love and acceptance. It is interesting also to realize that both children and parents expect more of visits from the church. They expect that the church will make them feel welcome and loved. This welcome and support needs to be provided along with any financial support that is given.

For most of the parents, the church was the only body that could provide them monetary support for their children's education, nutrition and some home needs. It was obvious that the little support that was received from the NGO was insufficient to carry on their daily lives.

Finally, the last research question discusses the ways the church can serve more effectively among children and parents living with HIV.

How do the Key Informants of the Study Perceive the Stigma Experience of Children and Parents Living with HIV and How the Church Can Serve as an Agent of Holistic Nurture for these Children and Parents?

[227] Interview notes of Parent-C, on 4th February 2015.

The previous research question reflected on the perspectives of children and their families' on the role of the church in providing support for those affect by the human immunodeficiency virus. This section considers the perspectives of the key informants—NGO leaders, doctors and pastors on the stigma experiences of families living with HIV and how the church can serve them. Their perspectives identify the understandings and practices essential for effective ministry by churches.

Developing Trust and Acceptance

D-1 is the Chief Executive Officer of a well-respected NGO. She works among the families living with HIV and her efforts are focused on anti-trafficking concerns. During the interview with her, she made a profound statement: "It takes a long trusting relationship for those living with HIV to find love and acceptance." Because of the confidentiality involved in the whole issue of HIV/AIDS, building up relationship takes time and it evolves slowly. This is true because those living with HIV are deeply hurt inside and they are very sensitive to any hurts from outside. Since they are already hurt from inside out, it is not easy for them to open up to anyone in church.

D-2 who treats the numerous infections related to HIV/AIDS in her patients, spoke about the pathetic condition that the children and families live in and how they face strong stigma in the community**.** The **c**hurch must find ways to show love and acceptance to make them feel comforted.[228] The doctors can provide medical support, but it is the

[228] Interview notes of Dotor-2, on 28th November 2014.

church that needs to step in as another family, walking alongside those who are stigmatized**,** extending an arm of love and acceptance.

NGOPL-2 stated that Christian NGOs offer this love when they visit in the homes of those who are suffering. He talked about the support groups that the NGO runs to provide residential care to patients**,** when required. Although the families that suffer stigma feel neglected in their own communities, visits from the social workers make them feel stronger and comforted. People from the church visiting in the homes of families who suffer the stigma of HIV could expand this ministry.[229]

Emphasizing the love expressed by the church, PAS-A explained that children living with HIV do not have friends in their communities or even in their own families. He told of an incident in which a person visiting a family stood outside the home with a cloth covering his face. He would not even drink water at their home. In contrast, when people from the church visited the family**,** "They sat with them, drank water and ate with them**.** The family felt loved and accepted."[230] The spirit of love and acceptance opens up a platform for the families living with HIV stigma to put their trust in the church as a body of warmth, love, and hope. PAS-C also claims that the "church must accept persons with HIV. They will feel welcomed only when we visit their homes and not just give them a hug when they come for Care and Share meetings."[231] Spending time with them at their homes will help to establish the fact that the church loves them and accepts them

[229] Interview notes of NGOPL-2, on 20th November 2014.

[230] Interview notes of Pastor-A, on 17th December 2014

[231] Interview notes of Pastor-C, on 3 February 2015.

with the love of Christ. The necessity of pastoral counseling and visits to these families was brought out as essential indicators of love and acceptance from the church.

On the other hand**,** there was a realization on the part of the pastors that many churches have failed to intentionally address the issue of HIV stigma. This has resulted in churches lacking in an understanding of the complex issues relating to HIV and how the church could be reaching out with love and support.

Other key informants spoke about the fear of discrimination that exists inside the church. When asked about her perspective of churches, D-3 mentioned, "It is hard to say because the Church has not come to a full acceptance of the whole issue of HIV. People living with HIV are finding it very hard to open up for fear of discrimination."[232] The very fact that they are vulnerable keeps them from opening up their lives to anyone who cannot be trusted, even within the circle of church members. Reflecting on what people with HIV experience at church, NGOPL-1 commented, "It depends on the church people and the pastor. Some people do not shake hands or even talk with them. Because of these strange behavior patterns people with HIV sometimes feel comfortable but at other times they are scared of their disclosure." NGOPL-1 observed that the sub-conscious behaviors of church members could create fear of being stigmatized in the hearts of people with HIV. According to NGOPL-3, the reason church members behave in these insensitive ways is because the pastors or leaders have not initiated to address the issue of HIV stigma with the people of their congregations.[233] Inadequate addressing of such delicate issues has posed the threat of disclosure of HIV.

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[232] Interview notes of Doctor-3, on 20th November 2014.

[233] Interview notes of NGOPL-3, on 23rd February 2015.

The key informants articulated their belief that children and families who face strong stigma at various levels look to the church as an arm that will extend love, acceptance and trust to them. However, they also note that this love and acceptance are not always offered.

Creating an Integrated Body of Worshiping Believers

The NGOs that are working for the families living with HIV provide them support systems as their way of ministering to them. Care and Share, offers such ministries to families with HIV. With the fear of being stigmatized, such families typically keep away from the regular mainstream worship in church.

Most churches have taken a back seat in addressing sensitive issues associated with HIV. Silence is often the option preferred rather than causing inconvenience among the members. Pastors or leaders of the team may fail even to speak out against negative attitudes or discrimination against those living with HIV. Speaking about the functioning of the church, D-1 noted that Care and Share meetings provide support groups but the individuals in these groups often have not yet been integrated with others in the church. She believes that if families with HIV experienced the church first hand, they would discover that it is a sanctuary.[234] D-3 also highlights this concern. The families "long to become participants in the regular worship where everyone attends."[235] In other words, the church must find ways to integrate families living with HIV into the fellowship of the church as a whole.

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[234] Interview notes of Doctor-1, on 3rd December 2014.

[235] Interview notes of Doctor-3, on 28th November 2014.

Similarly, NGOPL-2 who works with his doctor wife in a hospital, affirms that, "Support groups are not church…. We are not here to help them worship in support groups, that is not our ministry."[236] He further emphasizes that the church can prove effective in ministering to people with HIV only if the members are sensitized to the challenges involved in serving such people. Motivating the church to accept integrated worship is a challenge for leaders, as the pastors expressed in some of their interviews. Therefore pastors and leaders prefer silence rather than encountering negative responses to integrated worship practices.

However, leading a church into integrated worship is not impossible. PAS-A shared his experience of having people with HIV in his church. He chose not to reveal the HIV status of those attending his church. He simply integrated them into the mainstream worship services. In a voice of contentment and joy he shared, "Many patients are saved now and also serving as volunteers in my church. In my church there are ten percent who do not want to serve people with HIV, but ninety percent are willing to help and donate for this cause."[237] Despite the challenges he has faced in his church, PAS-A has been able to convince his church about the need to have integrated worship patterns. Frequent visits and an effort to include these families in the church can erase an attitude of discrimination. At the same time, families with HIV also feel comforted as they participate in the regular worship practices.

Overcoming Negative Attitudes

[236] Interview notes of NGOPL-2, on 20th November 2014.

[237] Interview notes of Pastor-A, on 17th December 2014.

While interviewing the key informants, I observed that doctors and NGO leaders had perspectives and understanding of which the pastors were unaware. While treating the patients with HIV, D-1 discovered that children do not open up easily because of what they have gone through with their peers. It is essential to develop meaningful relationships with them, so they can develop trust and ultimately experience friendship, thereby overcoming their sense of stigma.[238] The key informants also observed that a pervasive, unrelieved sense of being stigmatized affects a person's mental growth, especially in the case of children. They tend to withdraw in school, play areas**,** and social gatherings—settings in which physical, intellectual, emotional, and social development should be taking place. This lack of experience and development has a long-term impact.

When asked how he perceived the stigma experience of children and families with HIV, D-2 was reluctant to respond. He felt he could only help them with medical assistance, but helping them through the journey of stigma was beyond his capacity. He believed that it is only the church that can help children and families overcome the negative effects of the stigma they have experienced. I understood that he had no connections with the patients other than treating them for their multiple infections.

On the other hand D-3 serves with passion, caring for those suffering from HIV/AIDS. And she provides significant insights for pastors and NGO leaders to consider. She has discovered that "many children . . . who are young do not want to disclose their HIV status because of what they think they will face in their society." This fear of disclosure may come from observing their parents whose painful journey of HIV may have affected the children in many ways. D-3 shared the story of a man who lived

[238] Interview notes of Doctor-1, on 3rd December 2014.

for years with other residents in his building and was diagnosed with HIV very recently. He committed suicide because of fear of disclosure. This father's reaction to diagnosis affected his young son. The death of the father has caused great pain for the son, so now the young boy does not want to talk to anyone and instead keeps himself aloof most of the time. Since D-3 cannot fully meet the need of her patients on her own, she believes that it "is the church that can provide care for such people. We are called for this . . . but not many churches are willing to do this."[239] She calls the church to look into this matter with diligence because this is a primary call for the church—to serve the poor and needy. She feels the church can build bridges to help children and families with HIV to overcome the negative attitude toward them that they face in society.

The boy who had lost his dad to HIV could not cope with the stigma of his dad along with his own. Doctors who treat such individuals are helpless without someone to walk alongside them. Young adolescents and children not only keep things to themselves**,** but sometimes explode when their frustrations are more than they can bear.

It was interesting to see how the NGO leaders responded to the question posed. NGOPL-1 with his few years of experience feels that he sees the families with HIV living with negative attitudes. In fact, "they feel that somebody will think badly about them if they come to know."[240] There is a kind of internalized stigma. They fear being stigmatized and so they stigmatize themselves**,** withdrawing from others. D-1 agrees with

[239] Interview notes of Doctor-3, on 20th November 2014**.**

[240] Interview notes of NGOPL-1, on 15th December 2014.

this perspective. She noted that patients sometimes stigmatize themselves, and that is one reason why fear of discrimination still seems to exist.[241]

Each one of the NGO leaders felt that the church is the only body that can take care of such people. The Church has the call to serve the poor and needy and so it can minister to marginalized people with passion. Passion can be translated into action when the churches network with NGOs. NGOPL-2 regrets, however, that, as noted earlier, sometimes even churches can cause problems for people with HIV: "stigma is strong in the society, sometimes even in the churches."[242] When churches and pastors turn their backs on families with HIV and fail to understand and respond to their stigma experience, then those families experience a feeling of deep hurt. PAS-A pointed out that some people in the church have hurt these families, wounded them (*thech pohunchaya hai*) by not talking to them, or talking rudely and even by making them sit outside, treating them differently.[243] Therefore he believes that it is important to educate the church members. As long as this attitude of discrimination in the church continues to exist, the families who are experiencing stigma outside in the community are at risk of experiencing the same inside the church.

Talking about her experience in a church in Delhi, the capital of India, NGOPL-3 mentioned that the pastor of the English congregation did not allow her to speak about HIV awareness**.** Rather, he insisted that the Hindi congregation should take responsibility for such a ministry.[244] The attitude towards the ministry to the HIV-positive community

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[241] Interview notes of Doctor -1, on 3rd December 2014.

[242] Interview notes of NGOPL-2, on 20th November 2014**.**

[243] Interview notes of Pastor-A, on 17th December 2014.

[244] Interview notes of NGOPL-3, on 23rd February 2015.

is seemingly negative. Silence is the preferred option in many churches, rather than attempting integrated worship practices. Realizing his failure, PAS-C acknowledged that he had not attempted to encourage his church members or even propose an integrated ministry to HIV affected families in the regular services.[245] The work of NGOs such as Care and Share are limited to treating the disease and providing families with minimal support. The church is called to act as the body of Christ and do all they can to integrate into the church all people, including those living with HIV.

PAS-B, from the Hindi church, has worked for a couple of years directly with those who are HIV-positive and he also provides counseling. He shared about a lady who was involved in prostitution and she was also HIV-positive. The church people began to stigmatize her. They would not talk to her. They even wanted the pastor to stop her from coming to church. Some of them said they would not come to church if this lady and others like her showed up.[246]

PAS-B also mentioned that educating the church people is necessary, but it is significant to note that even some educated members of society practice stigma and discrimination against those living with HIV, as well. In fact**,** the educated do not want their children to mingle with families living with HIV. Educated church people were against such people who came to church. It is not education alone that eradicates stigma. Teaching about HIV/AIDS can be helpful, but it is God's love in the hearts of God's people that empowers them to share care and love those living with HIV.

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[245] Interview notes of Pastor-C, on 3rd February 2015**.**

[246] Interview notes of Pastor-B, on 14th January 2015.

PAS-B admitted that his church had not yet done anything to help children experiencing stigma. However, he personally took action. He "stood with the children in times of family crisis, spent time with them, and got to know their problems and issues and helped them find solutions."[247] It is his own passion that keeps him serving these little ones**.**

The church's ministries to those living with HIV are often more expressions of sympathy than intentional efforts to empower them. That is why fear of discrimination still seems to exist. NGOPL-2 contends that the church must involve people with HIV in leadership roles, such as in Sunday Schools, Youth Group or even on Church Committees.[248] This supports the idea of diffusion of authority in the congregation, as noted by Darin H. Land in his book, *The Diffusion of Ecclesiastical Authority*.[249] In selecting the seven leaders to minister to the widows in Acts 6, the honor of the early church was increased. Learning from the early church, the church today must consider leadership roles for the youngsters facing the challenges of HIV, thus empower them to be voice for others.

The NGOs and the doctors realized that it is the church that can best stand with children and families going through stigma. The medicinal healing from the doctors and the inner healing that the church can provide can bring holistic healing to such children and families. With the limitation of time and energy that the NGOs and the doctors face in their efforts, they realize that the church must play an important role to integrate the

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[247] Interview notes of Pastor-B, on 14th January 2015.

[248] Interview notes of NGOPL-2, on 20th November 2014.

[249] Darin H. Land, *The Diffusion of Ecclesiastical Authority: Sociological Dimensions of Leadership in the Book of Acts* (Eugene, OR: Pickwick Publications, 2008), 156-157.

families into regular worship practices. Thus the church can empower people to eradicate the negative attitude towards people living with HIV.

The key informants have indicated that the Church could be an agent for holistic nurture of the parents and children living with HIV/AIDS by developing trust and acceptance, by creating an integrated body of worshiping believers, and overcoming negative attitudes. This is a tall order but with the love of Christ in their hearts, the Church can become Christ's representatives to these people who desperately need help.

The findings of my research supported many of the perspectives found the review of literature and studies discussed in Chapter II.

Bloom in the book, *The Economics of HIV and AIDS,* observed that HIV, apart from being a threatening disease to health, has also devastated the economic stability of families. [250] All the respondents in the study suffered great economic impact. All the mothers, but one, were widows, so, the entire burden of the family came upon these women. They were all poorly educated, and what they were able to earn resulted in a hand to mouth existence for them and their children.

Nigel Marsh, in "Worse for Women," discussed the social and economic inequalities experienced by women making them more susceptible to disease, poverty, and stigma.[251] At least three of the children interviewed told of their parents being ill treated by their family members and the children themselves also had experienced stigma in their extended families. Most significantly, the mothers were culturally powerless and

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[250] Bloom, *The Economics of HIV and AIDS,* 4-5.

[251] Marsh, "Worse for Women," 12.

had to bear the blame for their husband's death. As Marsh claimed, the experience for women was worse than for the men. And since the women receiving this rejection and blame from their families and the extended communities were the ones left to care for their children, the way they were treated had an adverse impact on the children living with HIV.

Stigma is defined by Izabel as "a negative assessment of a person or an action associated with a particular object or an issue."[252] The children in this study were deeply aware of the fact that others viewed them negatively because of their HIV status. And this awareness led to negative responses from them. Some withdrew from their peers in fear of discovery and discrimination. Anger, denial, and shame griped the hearts of others.

Besides economic, social and psychological impact, there were also spiritual impacts on children and families living with HIV. Indians absorb deep spiritual insights,[253] and I saw this deep spiritual sensing in the mothers who were respondents in my study. One mother of three children was not welcome in her Muslim community because of being HIV-positive and keenly felt this rejection. But she felt welcomed at the Free Methodist Church and was comforted to be accepted in a place of worship. Some of the women expressed their desire to know about Jesus and started putting their trust in Jesus, when they came to Care and Share gatherings in the Free Methodist churches.

Some children going through stigma did not understand why God was inflicting them and their parents with HIV. They expected God to care for them, and they refused to put faith in a God they did not believe had taken care of their family.

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[252] Phiri, *Theology in the HIV and AIDS Era Series,* xi.

[253] Elkins, *Perspectives on the World Christians Movement*, 13.

Other children and families living with HIV looked to the church for hope, love and acceptance. They expected the church to be a body of healing, and even to be a caring presence by visiting in their homes. They hoped that the church would be the kind of NGO that Dan Brewster describes, one that "can be compassionate towards the suffering and the marginalized with the love of Christ."[254]

CHAPTER V

SUMMARY OF FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

This chapter provides a summary of the research, reflect on the conclusions that have been drawn from the findings of the study, and offer recommendations for implementation by NGOs and churches, and recommendations for further studies.

Summary of Findings

HIV/AIDS is a global issue that is posing tremendous threat and also has affected many people who are now living with HIV. India has the third largest HIV epidemic in the world. Despite the decline in HIV in India, more than 50 percent of the HIV-related

[254] Brewster, *Child, Church and Mission*, 41.

deaths in Asia are in India.[255] HIV prevalence in India is spread through major five states in India which are Nagaland, Mizoram, Manipur, Andhra Pradesh and Maharashtra.

While serving in the Free Methodist Church at Andheri East Mumbai, I became involved in ministering with people living with HIV. My heart was gripped with passion for these families and the need for the church to know better how to support children and families living with HIV/AIDS. To better serve families living with stigma toward children infected and affected with HIV, among the Care and Share project of Free Methodist Church, Andheri East, in Mumbai?

Statement of Purpose

The purpose of this study is to understand the impacts of HIV related stigma on selected HIV infected and affected children and their families involved with the Care and Share Project of the Free Methodist Church, Andheri East, in Mumbai, how they perceive the church's care for them, and to identify implications for the church's holistic nurture of children and families infected and affected by HIV. Children with HIV being the main respondents for this research, they will be the direct beneficiaries of this research. This study sought answers for the guiding questions for this study:

1. How do children infected and affected with HIV experience stigma?
2. How do the children infected and affected with HIV cope with the stigma encountered?

[255] "HIV and AIDS in India."

3. How does the parent's experience of HIV stigma impact the children's experience of stigma and coping?
4. How do children and parents infected and affected by HIV/AIDS perceive church as an agent of holistic nurture?
5. How do the NGO leaders, doctors and pastors in the study perceive the stigma experience of children and parents living with HIV and how the church can serve as an agent of holistic nurture for these children and parents?

Research Design

A qualitative study was conducted using two research methodologies to gather data, the case study method and key informant interviews. I developed case studies on children living with HIV by interviewing six children living with HIV, two from each age group of 8-11 years old, 12-15 years old, and 16-18 years old and their parents, mothers in most cases.

Key informant interviews were conducted with persons who work with HIV/AIDS affected families in the area of the Care and Share ministry, three medical doctors**,** three NGO Program Leaders, and three pastors, two pastors of Free Methodist Churches, and one pastor of a Baptist Church in Mumbai. The interviews of all the respondents took five months from Nov 14-Mar 15, following which the recorded data was transcribed and analyzed.

It is important to note that the conclusions and recommendations in the following sections can be applied to the children and families living with HIV in the Care and Share group. Recommendations are for the Free Methodist Churches to minister to the families with effective holistic approaches.

Conclusions

The study was guided by the five research questions listed earlier which focused on the stigma issues of children and families living with HIV. The conclusions will be presented as they relate to the five research questions.

Research Question 1: How do Children Infected and Affected with HIV Experience Stigma?

HIV stigma does affect the lives of children infected and affected by HIV in great measure. Interviews with the children in this study and their parents, clearly articulated that stigma is a life concern not only for adults, but importantly also for children. They go through stigma themselves and also share the stigma experienced by their parents. Children with HIV have a difficult time living with stigma experiences in their lives. This section will identify the various ways in which the children experienced stigma and were impacted by it.

Experiences of Rejection

All the children in the study identified the pain of rejection resulting from the stigma of HIV/AIDS. Apart from rejection in their families, they have also experienced it in their communities and schools. Three out of the four younger children involved in the study experienced the pain of rejection from their extended family. Young children did not understand or have words to describe this rejection. But they wondered why they were not loved as others in the extended family were loved.

Older children understood stigma and discrimination through their personal experiences of rejection in their families, schools, on the playground, and also in the community. They could name their experiences such as “taunts,” “teases,” from their

family members and "dirty words" from their friends at school and in the community. Sometimes, people "not shaking hands," or "not talking to them" in the communities were felt as stigma experiences by older children.

Rejection in the Family

For children their most hurtful experiences of stigma are those caused by their extended family members. The study discovered that they have suffered rejection by the extended families like grandparents, uncles, aunts and cousins. Children saw and experienced the rejection when extended family members did not visit the mother of the children in hospital. Other children in the extended family were not allowed to play with the children infected with HIV and they also taunted them.

Rejection in the School and in Church

Many of the children were very hurt when they experienced discrimination from their friends at school or even in churches. The fear of discrimination was high. They fear the stigmatizing behavior of teachers, and being rejected or treated badly by other children. In some cases teachers themselves were the cause of creating discrimination among the children and thus created fear in the lives of children with HIV.

The discriminating behaviors of the teachers and friends caused withdrawal and a sense of loneliness in the lives of children with HIV. In one incident, the child was rejected admission in school.[256] Fear of rejection was the main reason the children kept themselves aloof from friends in school and community.

Rejection in the Community

[256] Interview notes of Parent-D, on 8th January 2015.

Apart from the experience of rejection in extended families and schools, it is hurtful to know that children experience rejection in their own communities. Practices such as, "not talking well," "not shaking hands," "looking down [on them] as criminal," "chasing [them] out of the village, "were identified as gestures of rejection from the community. The rejection of the community was felt very strongly among the children and families living with HIV.

Fear of Disclosure and Discrimination

In addition to suffering from stigma related rejection, children experienced the pain and consequences of the fear of bringing stigma on themselves. Young adolescent children told of watching their parents' experience of stigma since they were very young. Journeying with their parents as they lived with HIV has created fear in the children. All the six children who were involved in the study mentioned that their parents instructed them to keep from disclosing their status to anyone. The children feared disclosure of their HIV status. Disclosure of HIV status would invite discrimination in the community. They suffered the fear of rejection before the rejection and discrimination occurred.

Disclosure came not just from speaking about their HIV status. Most of the children and parents commented that others notice when they fall sick frequently. Friends and teachers suspect there must be something serious behind their sickness. Fear of disclosure is added to the misery of the sickness. The ART medications taken by children who are HIV positive can also raise the suspicion of others. Out of fear of disclosure, some parents hesitate to talk to their children about their medications. Children are told to take the medicines without being told the reason for taking them. The child does not

know how important the medicine is, and may be careless about taking it. The fear of disclosure then negatively impacts the child's health.

Research Question 2:How do the Children Infected and Affected with HIV Cope with the Stigma Encountered?

In ministries to children and families with HIV, it is very important to understand how children cope with the whole issue of HIV and the stigma associated with it. In my interviews older children understood stigma and could talk about how they coped. However, younger children found it hard to understand the term "cope" so I used the simpler word "adjust" and that helped them respond to the questions better. The study revealed that most of the children found it very difficult to cope.

Coping Negatively

When I asked one doctor, "How do children cope with the stigma of HIV/AIDS," he answered, "They don't." All the Non Government Organization leaders and doctors confirmed this perspective that in most cases children had learnt to cope negatively.[257] All the parents and doctors interviewed in the study mentioned that it was very difficult for the children to cope without any assistance.

In schools when children experienced discrimination, they exhibited behaviors like withdrawal, aloofness, lack of friends**,** and choosing friends who are of bad influences in school and community. Older children as part of their growth looked for their identity in the wrong kind of companionship and were led into anti-social elements.

[257] Interview notes of NGOPL-3, on 23rd February 2015.

Another behavior that was seen was absence from school because of the fear of being questioned about the medicine children take in schools, or because of sickness or weakness. Children miss out on their sports days or any other physical activities in their schools because of their frequent sickness. They refuse to take their medicines sometimes at school because of fear of disclosure.

In the community where children live with their families, the attitude of discrimination by others has generated a sense of hatred in the hearts of children who are discriminated. When asked about his perspective about community reaction towards people with HIV, C-A (Age: 17yrs) responded, "I feel like killing them when they behave indifferent towards us with negative attitude."[258] None of the children interviewed mentioned receiving any assistance in coping with their negative feelings, and none of the parents mentioned giving such support to their children

The major cause behind the negative coping of children is the lack of support available to them. In most families living with HIV/AIDS the father is absent**.** This is a great loss of support for children. In the families, the absence of mother or father or even both, children had no assistance in positive coping. One of the older children C-A said, "When I was making the family model, I remember all the past days, when we used to be happy, my dad used to love me so much. When I see my uncle and aunty playing with their children, it hurts me to know that I do not have a dad to play with."[259] It is very difficult for the single widowed mother who is often sick herself to provide children with the support they need to cope with the experience of stigma. In all the cases in my study,

[258] Interview notes of Child-A, on 22nd November 2014.

[259] Interview notes of Child-A, on 22nd November 2014.

the mothers worried about their children being blamed or stigmatized in the community. Because they were concerned about the wellbeing of their children, most of the mothers carried the burden of keeping the family's HIV status a secret. Sadly, this attempt at secrecy deprived the families of the support they so desperately needed to cope with their experiences from stigma. Children are not told about their sickness. Parents understand about their HIV status and so try various means to cope, but since children do not understand about their health crisis and they are told to be quiet, they tend to think negatively about themselves.

Positive Coping Strategies

Two children who were involved in the study told of positive ways in which they were able to cope positively with their stigma experiences in their families, schools and communities. One way to respond to stigma was with an attitude of "let go" strategy and the other was by relating to each other living with HIV and helping them fight stigma.[260] The child was speaking in the context of discrimination in the community. When people in the neighborhood begin to have some negative feeling towards families living with HIV, the only way to face such attitudes was to "let go" or ignore them. This was a process that was happening in the lives of two families living with HIV. There was also another way to cope positively according to P-B. It was with the help of someone who cared about them. Children and parents infected and affected by HIV could cope positively when they had help with parenting.[261] It was interesting to discover that they were willing to help their own to cope with issues related to HIV.

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[260] Interview notes of Child-A, on 22nd November 2014.

[261]Interview notes of Parent- B, on 8th January 2015.

The third strategy that the children discussed was about the assistance from churches and NGOs. The study also revealed that children believe they could be assisted by churches, caregivers and NGOs in developing optimum coping skills. After relating to the Raju and Rani's stories, C-E (Age: 11) and C-C (Age: 12) suggested that the mothers of children with HIV must approach the church for help and NGOs for some livelihood for the family.[262] The younger children expected the church to help them "adjust" or overcome "bad treatments" in their families, schools and communities. By empowering and building up the self-esteem of the children, churches can stand with the children and families going through stigma.

Research Question 3: How Does the Parent's Experience of HIV Stigma Impact the Children's Experience of Stigma and Coping?

It is important to note that parents and children are inseparable in their journey of HIV; therefore all that the parents go through affects the children in every way. When parents are isolated from their support systems, children unconsciously participate in this isolation process, thus also suffer the unprocessed feelings that the parents go through. Therefore a significant understanding about parent's experience of stigma and its impact of children is required.

Parent's Experiences and the Impact on Children

All the mothers in my study mentioned that they were labeled as one who has "dirty disease," or "big disease," by their close family and also by extended family members. When P-C had lost her four babies to HIV/AIDS, none of her family members

[262] Interview notes of Child-E and Child-C, on 22nd December 2014 and 4th February 2014.

came to visit her at the hospital.[263] Her mother had left her to die at the hospital. At the disclosure of her HIV status the extended family discriminated not just the HIV-positive parent but also her entire family by using separate utensils for them during family gatherings. When children saw the extended family mistreating their mothers, they were overcome by shame within themselves and revenge towards their extended family members.

The extended families have reacted very negatively towards the mother and child after the death of the male figure in the family. When her mother chased P-B out of her home, her son could not understand this strange behavior of the grandmother. In the whole journey of the parent's experience of stigma, children have shared a large measure of their parent's hurt, bitterness, guilt and shame. Children whether young or old, become aggressive when they see parents being discriminated by their family members or community where they dwell.

There was fear of disclosure in the community. The families had a fear of losing friends. The parents told me, "If they [people in the community or the extended family] come to know that we are HIV positive, they will stop talking to us and stop playing with our children." This was one of the main reasons the parents preferred silence to disclosure.

Close observation of parent's experience of stigma had an immense impact on children. Unprocessed emotions and hurts absorbed from their parents have greatly impacted children in their psychosocial, emotional, spiritual and physical dimensions. Children were so hurt that C-A (age: 17) made a rigorous comment, "When a person

[263] Interview note of Parent-C, on 4th February 2015.

discriminates me, I used to think that they should also get HIV. I get angry and frustrated."[264] C-D (age: 13) also confirmed she was very angry at those who discriminated her mom. Anger was employed as a means of defense against discrimination. Anger in great measure had impacted all the older children from age 13-18 years.

Apart from anger, children were filled with fear of discrimination at school when they witnessed their parents being discriminated in their family and community. Sharing parents' stigma and their own pain of stigma experience led to aggression and resentment. The children carry the burden of their parent's experience as well as their own. It is an experience of double stigma for children. They were also children who have absorbed the negative attitudes from their parents.

Having experienced rejection from family, school and community, the children experience a huge level of stress. The mothers attempt their best to provide for their children within their limited resources. The mother becomes the only breadwinner in most of the cases. Being left with little or no supervision, the children look for their identity. This limited monitoring over children has affected their studies and behavioral practices.

All the children in my study were impacted by poverty and HIV that had deprived them of good living conditions and sound education. I was moved to hear about the negative impact of poverty and HIV on children. One of the pastors in my study had known a family that considered educating the children with HIV was a waste of money. Poor economic condition make coping difficult.

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[264] Interview notes of Child-A, on 22nd November 2014.

The faith of children also is in jeopardy. After they have seen and shared the parents' pain and sorrows, the children hesitate to believe in God. Their questions about suffering with HIV are unanswered. All the older children had problems trusting God with all the struggles they face in their lives.

Parent's Coping Impact on Children

In the process of coping the parent goes through guilt and overwhelming grief and they have a feeling that they are the reason their children suffer. The child again falls into a chain of guilt and shame. Coping with HIV stigma stood as a big challenge for parents living with HIV. In her early experience one of the mothers in my study had chosen suicide attempt as a matter of giving up on their lives.[265] This was the extreme step a parent could take to escape being stigmatized.

Parents have tried their best to cope with their stigma experience by being silent and in some cases, by committing suicide. This has led to a great psychosocial impact on children. As we saw earlier, parents have preferred silence to speaking out with courage to their children. This method of silence and hesitance in opening up with their children has posed greater fear of disclosure in the hearts of children. Most often the children have developed a sense of guilt and shame from the way their parents tried to hide their HIV status. Disclosure of their HIV status meant loss of friends for their children, loss of identity, and a life of shame because of HIV's association with sexuality.

Children who have seen their parents' struggle to cope have suffered great levels of impact in their lives. As a result, they endure guilt, anger, frustration, fear, revenge and shame in the process of coping. The older children reacted to their stigma experience with

[265] Interview notes of Parent-E, on 22nd December 2014.

an expression of revengeful spirit. In some cases, the parents and children could not handle the social isolation of the families, so children tend to suppress their anger and frustration, but yet live with a revengeful spirit in the community. It is observed that the stigma experience of the parents becomes a double-layered stigma with which children must cope, negatively or positively.

Research Question 4: How Do Children and Parents Infected and Affected by HIV/AIDS Perceive Church as an Agent of Holistic Nurture?

Since the direct beneficiaries of this study are children and families infected and affected by HIV/AIDS, it is necessary to understand their perspectives of church to be able to identify implications that when implemented will lead Free Methodist Churches in Mumbai into increasingly effective ministries of holistic nurture with children and their families living with HIV/AIDS.

Perceptions of Church

For all mothers but one, church is a place of warmth, love, and acceptance. In the society where there is a strong sense of discrimination and stigma, they feel rejected and marginalized. But when the families living with HIV began coming to Care and Share gatherings at Free Methodist Church Andheri, they felt loved and accepted. However, because of their experience in the broader community, it was hard to think that the church will not reject them if their HIV-positive status is discovered.

The interviews of selected children in the study revealed that they see the church as a body of healing. During the times of Care and Share gatherings, the children get to meet other children who are infected and affected with HIV and make friends. This is a

welcome contrast to the way in which they are often treated in their communities and at school.

Church was perceived as a source of healing, spiritual nurture, monetary support, love, and acceptance. All the mothers and children commented that they were accepted and felt relaxed at the Care and Share gatherings. They also receive a small amount for children's support, significantly towards their nutrition. Getting prayed for, during the three hours meetings at Care and Share was the spiritual nurture they received from church. However all the mothers and older children named other services they would appreciate from the church and the church-related NGOs. They believe home visits are very essential to the whole process of healing and nurture for children and families living with HIV. Five of the children in the study wished that people from the church would visit in the home to offer support and comfort for their mothers who were often sick**.** One of the children C-F (Age: 10) mentioned in her interview, "Please visit our home, pray for us more and help us live."[266] This desire suggests that visiting in the home would communicate a deeper level of caring and acceptance. Also they wanted the church people's visit to be role models to the community showing love.

Three mothers and four older children mentioned their self-withdrawal from the church because of the fear of being discriminated. One of the mothers in one of the Free Methodist churches was not feeling welcomed into the church when her HIV status was discovered, but later with the recommendation of the pastor she felt accepted into the Care and Share group.

[266] Interview notes of Child-F, on 30th December 2014.

The mothers and children discussed many positive perceptions about the church; however they also identified some concerns for greater effectiveness on the part of the Free Methodist churches and also the Church at large in ministry with families living HIV/AIDS.

Frequent visits from church members would ease the families' fear of being discriminated and fear of disclosure. Regarding spiritual nurture, more than offering mere prayers for children and families, they expect the social worker or church people to help them have a deeper understanding of God. Although most of them come from a non-Christian background, there is a sense of curiosity about understanding God as a healer and savior.

Research Question 5: How Do the NGO Leaders, Doctors and Pastors in the Study Perceive the Stigma Experience of Children and Parents Living with HIV and How the Church Can Serve as an Agent of Holistic Nurture for these Children and Parents?

Apart from knowing the perspective of church from the children and families living with HIV, the study also focused on how the key informants, NGO leaders, doctors and pastors perceived the stigma experience of those living with HIV. This will help the church to serve better as agents of holistic nurture.

Perceptions of Key Informants

In their interviews, the key informants, NGO leaders, doctors and pastors identified a critical issue, the importance of trust and acceptance. Trust and acceptance are not automatically extended to the church, or from the church, nor are they quickly developed. The key informants emphasized that the relationship between the church and the families with HIV requires gradual and careful growth. The interviews with parents

and children also confirmed this fact. It is not easy for a group of people who fear HIV/AIDS and may not understand the disease to offer acceptance to those who suffer with the disease. And it is not easy for those who have experienced rejection again and again to trust a group they do not know to accept them. This is a real challenge for the church and its holistic ministry to children and families living with HIV/AIDS.

The NGO leaders and the doctors saw the need of teamwork with the church. Their contribution, as they see it, is to provide medical care and to create a support system for families living with HIV. They believe it is the church's role to stand with children and families suffering with HIV stigma and help them face the truth of life with the disease and yet rise above the situation. In the society where people look down upon families living with HIV, there were times when some of the church members had visited them and ate with them. This was an image of love and acceptance that the church could express towards the marginalized. PAS-B mentioned that he was able to visit one of the

HIV-positive patient's homes along with a few of his church members.[267] The families drew strength from the church.

Challenges and Opportunities for the Church

In my interview with the pastors, it was apparent that none of the churches had intentional, carefully thought out plans for addressing the issues related to HIV and the stigma associated with it and for providing holistic nurture for families living with

[267] Interview notes of Pastor-B, 14th January 2015.

HIV/AIDS. Children and mothers felt that the church must create comfortable settings for people with HIV to share opening and deeply what they go through with respect to HIV, with others living with HIV. There were a few additional suggestions that came out of the interview:

First, provide congregations with a sound understanding of HIV/AIDS, how it is and is not transmitted, and what the families need from the church. Not all the churches have a sound knowledge about HIV/AIDS. Church as a helping agency must be aware of all the issues and challenges surrounding HIV/AIDS.

Second, foster a respectful caring view of the families. The study showed that the NGOs like Dayanand Foundation and others perceived families with HIV as recipients or mere beneficiaries of their services. Churches in general have perceived families with HIV as just dependent or mere recipient. All the older children,[268] mothers, and all the doctors in this study affirmed this perspective. Children and their parents sense this uncaring attitude. In this atmosphere, they fear that the church may look down on them because of their financial incapability and dependency.

Third, another fact that was discussed in the interview of the pastors was the church's failure to help children going through HIV stigma. Although the church had provided superficial monetary help to a certain extent, the process of empowerment is lacking in the church. The church must take a stand to reduce stigma in the lives of those living with HIV. In the context of Free Methodist Church, little has been done to empower the children and families living with HIV. They mentioned that adults in the church must support them.

[268] Interview notes of Child-A, Child-B, Child-D, on 22nd November 2014, 8th January 2015

Finally, the church has not made attempts to integrate the families ministered to through Care and Share into the life and ministry of the church. Without undermining the support system and care offered by Dayanand Foundation every fourth Thursday of the month, I believe that the Care and Share families must be integrated with the regular church worship services.

In the first chapter of this research I stated Goffman's perspective of stigma as a socially complex phenomena influenced my selection of the case study approach to my research design.[269] From the responses of the children and parents, the social complexity of the disease became very clear. In the second chapter, I discussed Goffman's identification of three types of stigma: (1) The abomination of the body with various deformities (2) the perceived blemishes of individual characters, such as dishonesty, weak will, betrayal, treachery, addiction, unemployment and other negative feelings (3) the stigma of race, tribe or even nation. This third type of stigma can be viewed in comparison to casteism, which is practiced in the Indian society. The families in this study experienced all three forms of stigma identified by Goffman.

Stigma as the "abomination of body," was not seen as physical and visible deformities, but the weak, fragile body of the mothers in the study represented this first category of stigma described by Goffman. Because of the mother's weak body, some children were also weak for lack of good food and care.

All the respondents had experienced the second category of stigma in the form of negative feelings towards them in many settings. All the mothers had experienced ill treatment at their work places and had suffered unemployment. The third kind of stigma

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[269] "Social Stigma," retrieved from http://en.wikipedia.org/wiki/Social_stigma, accessed on 25th March 2014.

that Goffman discusses is about race, tribe or even nation. People in India are socially associated with their respective caste and those associated with the lowest caste frequently suffer discriminated. All of the respondents in my study suffer HIV-related stigma and the added stigma of belonging to a lower caste.

Through this research study I have come to understand more fully the HIV-related stigma experienced by the children and their families. The following recommendations suggest how churches and NGOs can work together to more holistically support children and families dealing with the impact of the stigma associated with HIV.

The conclusions listed in the first part of this chapter clearly highlight the need for churches and NGOs to partner in ministries with children and families living with HIV.

The Care and Share ministry's origin was from the Marathi Free Methodist Church at Andheri. The pastor of the church was burdened with the passion to serve children and families with HIV. He shared his vision with the pastorate board and the ministry to families with HIV took shape. The pastor was already working with families living with HIV/AIDS, so it was easy for him to cast a vision about this ministry to the church board. After three months of his work among these families the church board approved little funds to support this ministry. This was when Care and Share officially began as a ministry to the families with HIV.

In the initial months of the ministry, the Pastor alone ministered to Care and Share group. A professional doctor and her team offered the medical support. Eventually after six months, the pastor's wife (me) also took initiative to join the ministry of Care and Share. They both motivated a few of the church members, especially the women, to work with this ministry.

In the beginning, the Andheri Free Methodist Church and Share and Care worked as partners. However, as time passed all the social activities of the church were given over to the NGO, Dayanand Foundation. Dayanand Foundation supports Care and Share members with a little monetary help. The church lost the vision and passion to be connected with the families with HIV.

Contributions to the Scholarly Community

This study, I believe, makes several valuable contributions to the expanding scholarly understanding of HIV-related stigma and ways of examining the issue.

First, as noted in Chapter 2, I found a significant number of studies exploring the impact of HIV-related stigma on adults, but very few studies that focused on the impact of HIV-related stigma on children. This study expands the understanding of children's experiences of HIV-related stigma and their response to those experiences.

Second, the findings of this research highlight the challenges of the extended life expectancy made possible by the medical treatment available to persons living with HIV/AIDS. The mothers who participated in the study had been living with HIV/AIDS for 13-23 years. But the stigma of HIV led to rejection from their families and communities and their fragile health made it difficult for the mothers to support their families. How to alleviate the extreme poverty these families experience needs to be addressed.

Third, a disturbing finding of the study was the attempted sexual violence toward mothers by sexually frustrated teenage sons who were also HIV-positive. One of the mothers in the study described her experience of her son's violence, one doctor, and one NGO Program Leaders spoke of this issue.

Fourth, the importance of partnerships between NGOs and churches was identified by the respondents. Both institutions have essential roles to play in supporting families living with HIV. Together they can provide holistic nurture for children and their families who must deal with stigma-related challenges.

Finally, the study demonstrates the value of the research methods used. The case study method that called for gathering data from the perspective of the children, the parents, and selected key informants provided significant insights into the socially complex issue of HIV-related stigma and its impact on children. The story telling and drawings used with the younger children and the "Family Constellation" activity used with the older children, proved effective. The methods helped the children express their thoughts and feelings and gave the research a glimpse into their experiences of HIV-related sigma. It is hoped that others can continue to build on the findings of this study.

Recommendations

This study provides recommendations to the church and the NGO and recommendations for further study.

Recommendations to the Church and the NGO

The following recommendations begin with a call to the church and the NGO to reestablish their ministry partnership, identify issues to be addressed, and present topics in need of further research.

The first recommendation is that the pastor of the Marathi Free Methodist Church in Andheri and the other Free Methodist Churches in Mumbai and the program leader of

Care and Share work together to reestablish and develop an effective ministry partnership between the church and the NGO. Possible steps in the process could be:

a. Dayanand Foundation can optimize the involvement of the churches, by inviting more participation of the key people in the churches. Representatives from women's groups, men's groups, youth and the church boards could be involved in planning meetings for families with HIV.
b. Doctors, nurses, and other medical assistants could be welcomed from the churches. Their contribution could be in treating the HIV patients with other multiple infections.
c. The NGO project leaders could organize occasional meetings in consultation with the pastor and the key church leaders to envision with them the goals and objectives of Care and Share ministries.
d. Once the partnership is reestablished it would be important for the project leader to see that pastors and key leaders participate in the Care and Share meeting as often as they could.

Reestablishing the ministry partnership of the Care and Share with the Free Methodist churches would take some time. However I see that the first step towards implementation would be to plan a meeting with each pastor and then initiate partnership in the later stage.

The second recommendation is that the pastor and a team of lay members intentionally address the issues related to HIV and stigma in the church, and that they include in the vision and mission of the church some ministries that would deal with the marginalized, including children and families living with HIV.

a. Intentionally addressing the issues related to HIV and stigma in the churches is crucial. Vision and mission of the church must spell out ministries to the marginalized, which would include catering to the children and families with HIV. It is important that the pastorate committee be well aware of their role in ministering to these families.
b. In addition to the occasional pulpit preaching, provide the members with handwritten goals of the church as a reminder of the ministries to be carried out.
c. The pastorate board, in one of their meetings, can have a family living with HIV speak out their expectations from the church and then add them into the implementation process of goals and vision of the church as is modeled by the apostles in Acts 6.
d. Pastor along with pastorate board will monitor and review the ministries of church from time to time. The review would be essential for the leaders in the church to look into opportunities to achieve the goals and visions pertaining to the ministry to families living with HIV.

The initiative to intentionally addressing of the issues related to HIV stigma must come from the leader. Each of the members of the pastorate board must be aware of the issues and challenges around HIV/AIDs.

The third recommendation is that pastors and lay people in the church be prepared to address the spiritual questions children living with HIV are asking. With all the suppressed emotions in their lives, children begin to raise many questions that have to be adequately addressed for holistic nurture. Some of the questions they raise are: “Why

God is afflicting me?" "Why has God taken away my mom and dad?" "How can I trust a God who is allowing my mom to suffer?"

a. The church leaders must increase their awareness of the spiritual question children are asking.
b. They must seek to understand theologically sound ways of responding to those questions that lead the children and their parents to come to know the loving God whom they can trust, and help them come to God.
c. Topics regarding human pain and suffering can be included as part of Sunday school. The teachers will need to become aware of the questions being raised by children going through stigma related to HIV.
d. Comfortable platforms can be created for children to open up their spiritual questions about suffering, pain and the hurts in life.

Helping the children with creative platforms to raise questions about their faith in God and then assisting them to process those questions is a ministry of inner healing will be a great service to them. If the NGO can identify children who go through hurts, the church can step in and help the children discover ways to come to God.

The fourth recommendation is to develop an intentional plan for educating families, church members, and the community in a sound understanding of HIV/AIDS.

a. The church and the NGO can design short courses on HIV/AIDS and teach the church members in small groups. It is important to be taught in smaller groups because that would allow venues for interaction and discussion.
b. I need to help people understand how HIV is and is not transmitted. Such teaching will help reduce stigma associated with HIV.

c. Educating the church about caring for those suffering with HIV and related stigma will equip the church to help children and families with HIV.

d. Have HIV discussions even in the Sunday school classes and observe how children react to these issues. Initiating discussion will create open floors for healthier discussion and thus the church can devise integrated curriculum for Sunday school classes. Education is not just the head knowledge that people would acquire about HIV, but instead the knowledge received by the church must be propelled towards action by passion in their hearts.

The fifth recommendation is to develop within the church a team of volunteers equipped and willing to provide support to families living with HIV/AIDS.

a. Mothers with HIV very often fall sick because of multiple infections. They expect the church members to visit their families and listen to their stories. The church pastor and pastorate board can identify people with passion and equip them for ministry among the families with HIV.

b. At times when children experience discrimination in schools, they expect the church to accompany them to school and stand with them. The Care and Share project leader can equip volunteers in the churches to do home visits and counseling.

c. The need of children advocates can be announced in Free Methodist churches and training could be arranged to equip them with counseling skills.

d. Apart from home visits and spiritual nurture, the church can call for people who are willing to offer financial support for families with HIV, maintaining the confidentiality of the families.

The churches may have very few people volunteering for HIV ministry. However it is significant for the leaders to make this initiative.

The sixth recommendation is that FMC NGO Dayanand Foundation work with Free Methodist Churches to raise volunteers for ministering to families with HIV through Care and Share and within the church.

a. Since all the respondents in my study mentioned home visits, it would be important for the Dayanand Foundation project leader to network with the church pastors and plan the visits.
b. Some financial support could be given by the NGO. Trained volunteers could offer the pastoral care and nurture from the church. A healthy partnership between the Free Methodist Church NGO Dayanand Foundation and the churches will strengthen the ministry to children and families with HIV.

The seventh recommendation is to develop settings and activities that provide children and families living with HIV/AIDS safe places to process the challenges of their lives, to understand better how to deal with those challenges, and to feel the support of others.

a. The Care and Share project team in consultation with the church pastor could arrange for children's camps, seminars or retreats where there will be an open discussion to understand the impacts of HIV stigma on children.
b. Open forums for young adolescent children must be organized by churches where sessions on stigma and discrimination could be addressed. The issues that children hesitate to open up at home with their parents or at school can be brought into light and addressed here.

c. The Free Methodist churches should take the help of young children living with HIV to plan programs in churches to address the stigma issues faced by families living HIV.

The involvement of church and NGO together to plan activities for families to process their challenges must be a long-term plan. The mothers who are widows, orphans and semi-orphans need a platform in churches to be heard.

The eighth recommendation is to equip children and families living with HIV to face the truth of their lives and to support them in the process.

a. Churches can offer programs to help the children to face the truth and live with dignity knowing that God uniquely made them. Also have seminars to train parents, especially the mothers, to disclose their status with great care. Sometimes the mothers take their ART in secret so that they would not be identified as HIV positive. Mothers need the guidance of the church and the NGO as they help their families cope with the challenges of living with HIV.

b. Successful biographies and documentaries of families facing stigma can be used in church gatherings to see the wider world of hope to the suffering and hurt.

Helping children and parents face the truth of their lives is a strong means of empowerment. Helping the children and parents together to face the truth together makes way for the family to live without shame and guilt.

The ninth recommendation is to find ways to gradually build trust between families living with HIV and the broader church congregation. Work toward incorporating children and parents living with HIV into the congregation.

a. For a trust relationship, it is important for the church people to visit the homes of the families living with HIV.
b. The support groups in the church could develop connection with each family and build a trust relationship with regular visits and counseling.
c. The initial step towards incorporating families into broader congregation could begin with smaller group gatherings with church members and the families living with HIV.
d. With gradual progress in the frequency of meetings, the families living with HIV can be incorporated with the broader church congregations.

The tenth recommendation is that NGO would seek to hire a female social worker. The following steps could be taken:

a. The churches could be informed about the need of female worker in the Free Methodist NGO, Dayanand Foundation.
b. Extra funding must be raised to hire a female worker.

Having a female worker in the NGO would give the Care and Share mothers someone with whom they can easily share their hearts and life experience. In my conversation with the mothers, they shared experiences that they did not feel comfortable discussing with the male social worker.

The final recommendation is that the NGO and church seek to come up with ways to help young adolescents cope with impact of HIV status on their sexual expression.

a. Peer based education assistance can be designed in the communities to address the sexual behavioral practices among young adolescents living with HIV.

b. Like all young adolescents, the 15-18 year olds in my study, experienced the awakening interest in sexual activities. The church must organize meetings in partnership with health care professional who can offer healthy advice for all young adolescents including those living with HIV.

Recommendations for Further Research

1. Further Research is needed into the psychological impact on children and early adolescents living with HIV/AIDS and how churches and NGOs can support the parents and children to cope with the impacts in healthy ways.
2. Further research is needed into the challenges of living with HIV/AIDS over many years and how families could be assisted in having the basics of life.
3. Research best practices and resources for ministry with children and families living with HIV.
4. Further research or models for ministry with children and families living with HIV.

APPENDIX A

INTERVIEW PROTOCOL FOR CHILDREN

Interview Protocol for Children Ages Eight to Eleven

Bridge conversation

To help the child become comfortable with the interviewer, use questions like the following:

Introduction questions

Greetings and basic information:

- “Hi, Can you please tell me your name?” “How old are you?” “Which school do you go?” “How was your school?” “How are you doing today?” These greeting level questions will help the researcher to lead into the essential talk. The whole conversation will take place in Hindi or Marathi language.

Reflections on drawing

To help the younger children to begin talking about their experiences and feelings, two methods will be used in the interview process. The children will be asked to draw a picture of their family, to draw a picture of school, and then tell the interviewer about the pictures.

Instructions:

While the conversation on their family is going on, give the child drawing materials and ask

- Can you please draw me a picture of your family?

After the child finishes drawing say:

- I like your drawing. Can you tell me about the people in your picture?

After they tell you about the picture, then follow up questions would be:

- How does the family feel?
- How do these members feel in this picture?

Point to the different people and features in the pictures and ask:

- Is anyone missing from the family picture?
- How do you think she or he feels?
- Why does he or she feel that way?
- Do any of these people feel like no one likes them? Can you tell me why?

- What do you think he or she would do then?

Give the child another piece of paper and ask:

- Now, can you draw me a picture of you at school, or in the neighborhood?

After the drawing, the children will be asked to explain what they have drawn it their picture, "Can you tell me about this picture?" The researcher will ask the children to reflect on the picture and explain them.

Samples of Possible follow up questions

- Can you tell me about this (point to) person?
- I wonder why those children are over there, and these children are here?
- Do they ever play together?
- How does that make the children feel?
- Can you draw a picture of yourself at your school or playing in your neighborhood? The idea would be to get a picture of their feelings about life and relationships or any sense of stigma in both settings. (This would be a second picture if the child has not included him/herself in the first one.) Good

Reflections on story

To help the children interact more on theirs and others feelings related to HIV, the interviewer would tell the children a story and engage them in talking about the story.

Instructions:

- Tell the child the following story, using the name Raju for boy and Rani for girl.

Story

Raju who was nine years and his sister Rani eighteen years old lived very happily with their parents and grandparents in a small village. Father was a truck driver and so

had to travel to far off places to earn for the family. Mother was a housewife taking care of Raju and his sister Rani. One day his father came home complaining that he was feeling sick. His health conditions became worse and after eight or nine months of treatment he died of AIDS. The neighbors now started talking bad about this family. As the days passed by, Raju and Rani realized that the behavior of their grandparents towards them was very different. The children were denied hugs from their grandparents and other relatives too. A few months later, Raju and Rani along with their mom were chased out of their home. Even the villagers did not want to have them in their village. Raju and Rani started wondering why their grandparents who once used to love them so much are now so indifferent. Helpless as they were they had to go out of their home and so they had to take help from an NGO to find a little house for them away from their grandparent's home.

Following the story, use the following questions to help the child reflect on the story:

- How do you think Raju and Rani felt? Why would they feel that way? How do you think Raju's mother would have felt about the whole situation?
- Why do you think the grandparents and villagers sent Raju, Rani and their mom out of their home?
- How might the family cope (adjust) with such situation? What could the family do to make things better? What could Raju do to make things better?
- How do you think the church could help Raju and Rani and their family? What do you think the church can do for such children and families in situations as such?
- Have you been to church? Why? Why not?

Carefully record all their answers in the case notebook. Also keep a voice recorder to review the information collected. (Be conscious that note taking does not distract the child or the researcher from listening to the child. The other option is to note down everything right after the interview is over).

- While narrating the story, carefully observe the child's facial expression, body language or any other reactions. This must be recorded right when the story telling time with the children is over. The interviewer will intentionally observe for expressions that would indicate feelings like, "hurt" or "offense.

Interview Protocol for Respondents Who Are 12 to 15 and 16 to 18 Years Old

Initiate the conversation with self-introduction. The researcher will give a self-introduction and explain what the study is about. Then explain the purpose and the outcome of the research.

After a formal introduction ask the child:

- Can I please know your name? Can you tell me about your family?
- Where do you stay? Which school do you go?

Following these informal talks asks the child:

- Can I ask you a favor? Would you please make a model of your family on this board?

Introduction to "family constellation"

"Family constellation" is an activity where the child will be offered clay to make models or figures that would represent his or her family members. The children will be allowed to arrange a home/family scenario in the "family constellation" activity and then

asked to explain the process. The researcher will record the observation and remarks of the children in this activity.

To interviewer will use “family constellation” activity to help the child relate their past to their present or to relate to any incident that might have occurred in their families.

At the beginning of the conversation, children will be engaged in “family constellation” activity to talk about their families. The researcher will carefully look into how the children are involved in this individual activity and later ask them to explain what they did. Ask them to reflect upon this particular activity.

Instructions:

Provide color clay and a cardboard to the child, engage the child in “family constellation” activity, and say:

- Can you make figures or clay models of your family members?
- Can you create your family a scene of your family doing something or just being together on this family board? May be you can make a model when your family was happy.

Carefully look into how the child is involved in this individual activity and later ask him or her to explain the family scenario.

Ask some follow up questions after this activity:

- Can you talk about these members that you have made on this board?
- What were you feeling while constructing this family model? What was going on in your mind as you while making these figures?

After the “family constellation” activity, initiate talk about the child’s school. Use the following questions in a semi-structured interview:

- How do you like your school? Can you tell me something that you like about your school?
- Is there anything that you dislike about your school? Can you describe why?
- When kids at school find out that another kid has HIV how do they respond?

Community/neighborhood response:

The following questions are designed to understand the child's perspective on community/neighborhood's response to people living with HIV.

- How do people in your community treat families with HIV/AIDS?
- How does that make a person feel?
- Have you ever experienced such things? Can you tell me about that experience?
- Do you think your parents have experienced such kind of bad treatment (stigma) from within your family or outside?
- What are some examples of those experiences?
- To whom do you think a person with HIV is most likely to disclose his or her status? Why?
- How can the children and families living with HIV cope with the bad treatment (stigma)? Or how will they manage or overcome such situations?
- How do you think churches treat families with HIV?
- Can you tell me about a bad experience you have had with a church? Can you tell me about a good experience you have had with a church?
- What would you like (do you expect) a church to do for you or your family? How can the church be more effective in ministry to people living with HIV?

- If you were to open an NGO for children and families living with HIV, what do you think you will do? (This question was added after the pilot study, so these inputs from a child can be added in recommendations for Care and Share.

APPENDIX B

INTERVIEW PROTOCOL FOR PARENTS

The researcher will thank the parents for their permission and begin the conversation with the health talk of their friends and then initiate the semi-structured interview using the following questions:

- How is your health?
- How is your friend who lives with HIV doing?

- How is she coping with the whole situation of living with HIV?
- How do people in your community treat families with HIV/AIDS? How has the community treated you and your family?
- Can you please tell me about experience with HIV? (This is very emotional question for the parents, especially the mothers)
- Have you ever experienced ill treatment from your family?
- What are some examples of those experiences?
- How does your experience with HIV impact your children?
- To whom do you think a person with HIV is most likely to disclose his or her status? Why?
- Do people living with HIV suffer from stigma? Have you experienced stigma?
- Has your child experienced stigma? Can you tell me about some of his/her experience? How do you think those experiences impacted him/her?
- What does it to do to a person or a family?
- How can the children and families living with HIV cope with the bad treatment (stigma)?
- How do you think churches treat families with HIV?
- Can you tell me about a bad experience you have had with a church? Can you tell me about a good experience you have had with a church?
- What would you like (do you expect) a church to do for you or your family? How can the church be more effective in ministry to people living with HIV?
- What difference has Care and Share made in your life?
- What can be done more by Care and Share for the people living with HIV?

APPENDIX C

INTERVIEW PROTOCOL FOR DOCTORS

Interview questions

1. Can you please describe how you got involved with caring for persons with HIV/AIDS?
2. How does the living condition of parents living with HIV impact a child?
3. What is the attitude of hospital staff towards HIV patients?
4. Do you think people living with HIV experience stigma? Can you site some incidences of stigma experiences that children/families go through?
5. How do you think the parent cope with such stigma experiences?
6. How do children cope with stigma?
7. Does stigma experience of parents have impact of their children? Can you explain about it?
8. How do you think people living with HIV/AIDS feel about the church? Why?
9. What do you think churches could do to nurture children living with HIV?
10. How could they help reduce the stigma experienced by a child and the family?

APPENDIX D

INTERVIEW PROTOCOL FOR NGO PROJECT LEADERS

1. What is the goal of your NGO with respect to ministering to the people living with HIV?
2. Do you think families living with HIV suffer stigma? How does that impact children and families? Can you describe some examples?
3. How do you see children coping with stigma of HIV?
4. How do you think parents cope with such experiences in their societies?
5. Do you think the stigma experience of parents have impact on their children? Explain.
6. What role do Christian NGOs play in the lives of people living with HIV? How do you address the issue of stigma?
7. How do you help children and families cope with stigma?
8. How do you think people living with HIV/AIDS feel about the church? Why?
9. In what ways can the church improve its effectiveness in ministering to the children and families living with HIV/AIDS?

APPENDIX E

INTERVIEW PROTOCOL FOR PASTORS

1. What is your personal experience of ministering to children and families living with HIV, if you have any?
2. What is the goal of your church with respect to ministering to children and families living with HIV?
3. How do you think the stigma related to HIV impacts children and their families? Can you describe?
4. In what way do you think the stigma experience of families affect children?
5. How do you think people in churches feel about those who live with HIV/AIDS?
6. What do you think influences the attitudes of people in the church toward persons living with HIV/AIDS?
7. How can the church effectively minister to children and families living with HIV, significantly with reference to their stigma experience?
8. What challenges do you think a pastor will face if he or she tries to lead a congregation into ministry with families and children living with HIV/AIDS?
9. How might those challenges be overcome?
10. How do you think people living the HIV feel about the church? Why?

APPENDIX F

INFORMED CONSENT LETTER FOR PARENTS

Dear _____

You are kindly asked to allow _____to participate in the research study I am doing to better the experience of children and families living with HIV/AIDS. The purpose of the research is to help Free Methodist Churches know how to better provide care for children and families living with HIV/AIDS. I will be interviewing children between the ages of 8-18 and the parent of each child. If you agree to give consent for _____ to be in the study, _____will be invited to meet with me for one interview conversation that will last 45-60 minutes.

The conversation will be recorded for use in reflecting on the child's insights but will be deleted following the completion of the course assignment. In any presentations and/or reports on the research, no child or parent will be individually identifiable. All participants' identities will be protected. If anyone else is given information about your child, they will not know {his or her} name. A number or initials will be used instead of a name.

You can ask me questions any time about anything in this study. The children in the study can also ask their parent any questions they might have about the study. Signing this paper means that you have read this information or had it read to you, and that you and your child are willing to be in the study. If you do not want to be in the study, do not sign the paper. Being in the study is up to you, and no one will be mad if you do not sign this paper or even if you change your mind later. You agree that you have been told about this study and why it is being done and what to do.

Thank you for considering my request,

Stella Bokare
Researcher

_____ _____
Signature of Parent Agreeing to Child Being in the Study Date Signed

_____ _____
Name of Child Who Verbally Agreed to be in the Study Date

APPENDIX G

INFORMED CONSENT LETTER FOR NGO PROJECT LEADERS, DOCTORS, AND PASTORS

Dear _____

You are kindly invited to participate in the research study I am doing to better the experience of children and families living with

HIV/AIDS. The purpose of the research is to help Free Methodist Churches know how to provide better care for children and families living with HIV/AIDS. I will be interviewing three doctors, three NGO leaders and three pastors for this study.

If you agree to give consent, you will be invited for an interview meeting with me that will last for 45-60 minutes. The conversation will be recorded for use but will be deleted following the completion of the course assignment.

In any presentations and/or reports on the research, the participant's name will not be individually identifiable. All participants' identities will be protected. A number or initials will be used instead of a name.

You are welcome to ask any questions to the researcher any time regarding the interview in the study.

(Signing this paper means that you have read this information or had it read to you, and that you and your child are willing to be in the study. If you do not want to be in the study, do not sign the paper).

I,_____(name) have read the above information and I freely agree to participate in this study.

Thank you for considering my request,

Stella Bokare
Researcher

_____ _____

Signature of the Participant Date Signed

APPENDIX H

OBSERVATION CHECKLIST

Date of the Observation: _____

Place: _____

Name (Code) of Respondents: _____

Time of Observation: _____

Observer: _____

Observation Notes:

_____

_____

_____

_____

_____

The following are some of the things I observed during the field research:

1. Description of the setting,
2. Behavior and expression of the responents
3. Non-verbal cues of the respondents
4. My feelings while doing the interviews

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PhD in Holistic Child Development	Asia-Pacific Nazarene Theological Seminary (2016)
Master in Divinity	Union Biblical Seminary, India (2009)
Master of Arts (English)	Chennai University, India (2006)
Bachelor in Arts (English)	Chennai University, India (2004)
Bachelor in Theology	Y.C.L.T, India (1995)
Higher Secondary School	Tamil Nadu, India (1992)

Work Experience

International Child Care Ministries (2013-present)

- Presently working as South Asia Regional Coordinator in International Child Care Ministries (ICCM) overseeing the work of ICCM in India, Nepal and Bangladesh.

Alternative Learning System (ALS) Counselor and Instructional Manager: 2010-2012

- Empowered girls rescued from trafficking. Worked at APNTS with Visayan Forum, Philippines.

Associate Project Coordinator: Mumbai (2006-2009)

- Mobilized churches to trigger supportive care for people affected with HIV/AIDS, partnering with Free Methodist Churches and Association for Christian Thoughtfulness (ACT) Chirag-a Christian NGO in Mumbai, India;
- Created a micro finance project as livelihood initiatives for the HIV/AIDS affected families;

- Presented annual reports of the project to the Administration Board of Free Methodist Church of West India Conference (WIC);
- Provided health care clinical aids and medicine available with the assistance of doctors team for the HIV;
- Initiated spiritual nurture through voluntary involvement of the FMC lay leaders; and
- Advocated for the rights of women and children

School Network In charge: (2004-2009)

- Headed the English Department Ministries, Scripture Union, Mumbai India Organize HIV awareness seminars and workshops schools connected to the ministries of Scripture Union;
- Coordinated meetings with the institution heads for the purpose of organizing HIV awareness among the parents and students; and
- Conducted parenting seminars to initiate a participatory orientation of the project

Teaching Experience: (1996-2003)

- Taught at Divine Light School, Mumbai, India;
- Led the Parent Teachers Association in propagating a healthier view of parental responsibilities in the career development of students;
- Taught English subject to the girls rescued from trafficking with Alternative Learning Centre at APNTS, Philippines.
- Taught at Mount Gibeon High School, Manipur, India (1992-1995)
- Taught at Okai Academy, Manipur, India (1996-1999)

Volunteer Involvement Experience

- Kids Club Instructor at Asia-Pacific Nazarene Theological Seminary (2009-2010)
- Secretary for the Executive Board on NGO- Dayanand Foundation (2008-2009, 2014-present)
- Children's Ministry Co-coordinator: Western India Conference of Free Methodist Churches in Mumbai (2000-2004)
- Rehabilitation Project in Leprosy Mission Mumbai Chapter One (2002-2005)

Trainings

- HIV/AIDS Awareness Training Among Schools and Colleges in Mumbai (2005-2009)
- Workshops and Seminars on Education
- Advanced Leadership Training with Haggai Institute, Mumbai India (2004)
- Career Development Seminars with Scripture Union India (2005-2009)
- Alternative Learning System in the Philippines (2010-2012)

Language Proficiencies:

- English, Hindi, Tamil, Marathi

Publication:

- "Teenage Pregnancies in Philippines: Implication for Intervention Strategies for Children in Trauma." *Journal of Asia Mission* 13, no. 1 (May 2012): 83-97.