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Impact of Parent's HIV Status on Their Uninfected Child—A Comparative Analysis of the Child's Healthcare Utilization, Access and Health Outcomes

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Abstract

With the advent of effective antiretroviral medication and increased expectancy of life span among HIV-infected individuals has lead to an increase in the at-risk population of uninfected children living with their HIV-infected parent(s). The purpose of this study was to investigate the impact of parent's HIV status on their child's access to healthcare resources, healthcare utilization and health outcomes.

This was a cross-sectional study in which the information on the children of HIV seropositive parent(s) was collected through a face-to-face interview of the HIV-infected parents having children currently residing with them. The comparative group comprising of children of HIV seronegative parents was obtained from the Medical Expenditure Panel Survey (MEPS) 2006 database. HIV seronegative children aged between 2 yrs and 15 yrs of HIV seropositive as well as HIV seronegative parent(s) were included in this study. A parent was identified as HIV seropositive if they had a prior diagnosis of HIV/AIDS (ICD-9-CM 042, 043, V08) by a physician and had at least one record of a HIV positive serological test result in the past 6 months in their medical records. A parent was defined HIV seronegative if there were no diagnosis of HIV/AIDS (ICD-9-CM 042, 043, V08) in their medical records in MEPS 2006 database. Each child of HIV seropositive parent (primary group) was matched with two children of HIV seronegative parents (comparative group) using the Mahalanobis Distance Metric matching including the propensity score technique. Bivariate and two step multivariable logistic and negative binomial regression analysis was conducted to assess the relationship between the parent's HIV status and potential variables of interest.

Upon matching, 89 children of HIV seropositive parent(s) matched with 178 children of HIV seronegative parents (1:2 ratio), thus making the final study sample of 267 participants. No differences were observed between the groups in terms of their mean age (8.47 vs 8.94 yrs, p=0.6265), parent's age (33.57 vs 34.21 yrs, p=0.9464) and other socio-economic and parent's health insurance variables. This study found no difference between the children in terms of their access to health insurance (97.75% vs 96.63%, p=0.7227) and access to regular source of medical care (87.64% vs 86.68%, p=0.4453). However, a larger number of children of HIV seropositive parent(s) had prescription insurance (95.51% vs 16.29%, p=<0.0001) compared to children of HIV seronegative parents. Also, children of HIV seropositive parent(s) took more time and expressed having difficulty in getting to a healthcare provider compared to children of HIV seronegative parents. Children of HIV seropositive parent(s) were 1.682 times (95% CI: 1.115-6.453) more likely to have a physician visit and had 49% (p=0.0206) more visits to a doctor than the children of HIV seronegative parents. No differences were observed in the likelihood of the children in having a hospital visit or an emergency room visit. However, among children who had a hospital visit and among those who had an emergency room visit, children living with their HIV seropositive parent had 3.0 times more hospital visits (p=0.0244) and 86% more emergency room visits (p=0.0464) compared to children living with HIV seronegative parents, respectively. No relationship was noted between the parent's HIV status and the child's absenteeism in school/daycare due to illness (OR: 0.938, 95% CI: 0.425-2.069). However, children of HIV seropositive parent were 4.041 times more likely (95% CI: 1.887-13.471) to be overweight. Though no difference in the likelihood of these children being currently on prescription medication was observed (OR: 0.918, 95% CI: 0.413-2.042), among those who were currently on any medication, children of HIV seropositive parent(s) were more likely to be on a medication for a mental health problem (OR: 5.520, 95% CI: 1.503-20.276).

This study concluded that HIV status of the parent has significant impact on the child's access in getting to a healthcare provider. It was also found that children of HIVinfected parent(s) had higher utilization of physician's visits. Higher incidences of obesity and consumption of psychotropic medications among children of HIV seropositive parent(s) signify serious impact of the parent's HIV status on the nutrition and psychological growth of the child. Further studies are recommended to investigatethe exact cause and long term impacts of the findings observed in this study.

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IMPACT OF PARENT'S HIV STATUS ON THEIR UNINFECTED CHILD — A COMPARATIVE ANALYSIS OF THE CHILD'S HEALTHCARE UTILIZATION, ACCESS AND HEALTH OUTCOMES

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Doctor of Philosophy
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By
Arijit Ganguli
December 2009

DEDICATION

This work is dedicated to my wife, son, and family members for their selfless support; love, encouragement, and understanding that have been the source of my courage, determination and belief in my journey to accomplish this long-lasting life goal.

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ABSTRACT

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LIST OF ABBREVIATIONS

AHRQ	Agency of Healthcare Research and Quality
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral Drug
bDNA	Branched Deoxyribonucleic Acid
BMI	Body Mass Index
CBCL	Child Behavior Checklist
CCR5	CC Chemokine Receptor 5
CD4	CD4+ T Cell Lymphocyte
CDC	Center for Disease Control and Prevention (United States)
CHQ	Child Health Questionnaire
CI	Confidence Interval
DHHA	Department of Health and Human Services
DNA	Deoxyribonucleic Acid
DNA PCR	Deoxyribonucleic Acid Polymerase Chain Reaction
DPT	Diphtheria, Pertussis, and Tetanus
DTa	Diphtheria, Tetanus, and [Acellular] Pertussis
DT	Diphtheria, Tetanus
ELIZA	Enzyme-linked Immunosorbent Assay
ER	Emergency Room
EIA	Enzyme Immunoassay
GED	General Education Diploma
GHS	General Health Subscale
HAART	Highly Active Antiretroviral Therapy
HBV	Hepatitis B Virus
HCSUS	HIV Cost and Service Utilization Study
HIV	Human Immunodeficiency Virus
HIV AN	Human Immunodeficiency Virus Associated Nephropathy
HRSA	Health Resource and Services Administration
ICD	International Classifications of Diseases
IDU	Intravenous Drug User
MD	Mahalanobis Distance
MEPS	Medical Expenditure Panel Survey
MMWR	Morbidity and Mortality Weekly Report
MMR	Measles, Mumps, and Rubella
NMES	National Medical Expenditure Survey
mRNA	Messenger Ribonucleic Acid
NHIS	National Health Interview Survey
NHSDA	National Household Survey on Drug Abuse
NICHD	National Institute of Child Health and Human Development
NMIHS	National Maternal and Infant Health Survey
NNRTIs	Non-nucleoside Reverse Transcriptase Inhibitors
NRTIs	Nucleoside/Nucleotide Reverse Transcriptase Inhibitors

OARAC	Office of AIDS Research Advisory Board
OR	Odd Ratio
PLWHA	People Living with HIV/AIDS
PI	Protease Inhibitors
PS	Propensity Scores
RNA	Ribonucleic Acid
RNA PCR	Ribonucleic Acid Polymerase Chain Reaction
RR	Rate Ratio
RX	Prescription Medication
STD	Sexually Transmitted Diseases
tRNA	Transfer Ribonucleic Acid
UNAIDS	United Nations Joint Program on HIV/AIDS
UT-IRB	University of Tennessee Institutional Review Board
WHO	World Health Organization
YSR	Youth Self Report

CHAPTER 1: INTRODUCTION

"Let us sacrifice our today so that our children can have a better tomorrow."
- Dr. A.P.J. Abdul Kalam
(11th President of India, President's Speech to the Nation, August 14, 2003)

Human Immunodeficiency Virus, known to the world as HIV, has been a menace disease to the human race since its detection. With the disease now attaining the status of a chronic illness, the impact of HIV has stretched itself through time. The world, which still wrestles the virus in form of infected people, now has to organize itself to deal with a new populace of individuals affected by this disease. With the increase in the survival span of the HIV-infected individuals, a new generation comprising children has emerged that faces the far reaching consequence of the disease. Children are one of the silent recipients of the indirect effects of the disease. Children of HIV-infected parent(s) face severe community discrimination, emotional deprivation, psychological trauma, economic hardships, abuse and a bunch of superfluous and harmful circumstances that hinders their natural growth. By impacting these children HIV has now found its way to lay its spawn into the next generation.

1.1 Background

Studies show more than a quarter of women younger than 30 years conceived despite the knowledge of their HIV positive status.[1] Current estimates suggest that nearly 28% of HIV-infected adults under medical care have one or more children less than 18 years, and many of these children currently stay with their HIV-infected parent(s).[2] Reports claim an alarming fourfold increase, from 6.5% in 1985 to 26% in 2005, in the population of women among the newly infected HIV cases in the past 20 years.[3] Seventy nine percent of the newly infected HIV women, between 2000 and 2005, were in the childbearing ages of 20 to 44 years old.[4] Strong desire and commitment for bearing a child was observed among HIV positive women in their child bearing age, very similar to uninfected women.[5,6] With the advent of the highly active antiretroviral therapy (HAART) the life expectancy among the people living with HIV/AIDS (PLWHA) has increased tremendously in the past decade.[7,8] Appropriate treatment adherence decreases the risk of mother to child transmission of the infection. This has been identified as a significant factor for the current surge in the parenthood status among PLHWA.[1]

Conceptually health of parent(s) is a significant predictor of the health of a child.[9] According to Grossman's human health capital model every person produces their health.[10] An extended theory of this concept, which took family as a unit, found the health status of the parents to be an important determinant in the child's production of health.[9] Children of parents suffering from somatic illness have high probability of developing behavioral and psychological problems.[11] This fact may be true for HIV-infected population and the HIV status of parent(s) can have a significant impact on the health of the child. It is true that the state of mental health of the uninfected child has been found to be significantly dependent on the health status of the HIV-infected parent.[12] A recent study has also shown that school age children of mothers suffering from late stage HIV/AIDS suffer from significant psychiatric and/or behavioral symptoms.[16] High risk of incidence of traumatic and unexpected, noninfectious deaths in children born to HIV-infected parents has also been documented.[13] It is postulated that the viability of home care relies greatly on the willingness and ability of the caregiver, predominantly women, to provide adequate care and upbringing of their children.[14]

HIV-infected families face severe economic hardship and this can mean long term detrimental consequences for their children. In the initial stages of the disease the impact of the disease is minimal, however as the health of the parent deteriorates the care demands of the person increases. Disability in performing routine household work and physical impairments is commonly observed in late stage HIV/AIDS patients and meeting the expectation of their family becomes difficult.[15] This then has a direct impact on the economic productivity of the person. At the same time the household faces an increased cost of treatment. Literature identifies loss of household income, possibility of migration, loss of formal education, impact on nutrition, emotional deprivation, social abuse and exploitation and even rapes and exposure to domestic violence, as a few of the long term consequences faced by children in HIV-infected families.[16]

Contrary to these observations, being infected with HIV, some parents have been seen to be more judicious and efficient in their caregiver's role, something which the literature identifies as 'defensive mothering'.[17] A study has also shown that one third of the HIV-infected parents had proper guardianship planning for their children, less than seen in the general population.[18] Ross et al., in their study found that the HIV status of mothers does not adversely affect the physical growth of the child in the first 3 years from birth.[19] A similar study that followed children up to the age of 10 yrs showed a lower growth rate among children born to HIV-infected mothers.[20] However, literature lacks studies on the healthcare utilization among these children, especially among US population. The current literature acknowledges the growing population of children living with their HIV-infected parents but lacks adequate information concerning its impact on healthcare utilization and health outcomes of these children. This virus (HIV) has been known to erode the productive capacity of the current generation. Due to the increase in the newly emerging HIV-affected children, this disease seems to be eroding the health of the next generation.

The most comprehensive government policy catering to the HIV-infected as well as affected population in the Unites States has been the 'Title XXVI of the PHS Act', previous known as 'Ryan White Care Act'.[21] Authorized in 1990, this act initiated the Ryan White HIV/AIDS program executed by the Health Resources and Services Administration (HRSA) and estimated to benefit more than half a million people annually.[22] The program aims to provide health care coverage and financial assistance to those coping with HIV/AIDS disease. After Medicare and Medicaid, this program is the third largest funding source of the government for HIV/AIDS care in the United States.[23] Policy analysts have repeatedly felt the deficiency of having a family-centric approach instead of the current individual-centric dogma in the policy.[24,25] Also the policies do not address the disease associated issues of social stigma which still hinders the effectiveness of the program especially in children and youth affected by HIV.[25]

1.2 Statement of Problem

The current increase in the numbers of uninfected children living with HIV-infected parents has given rise to a population that has been scarcely studied.[7] Little has been known about the healthcare utilization and health outcomes of these children. Low income, low level of education and unemployment has been associated with the prevalence of HIV.[26] Prevalence of food insecurity is almost five(5) times greater among HIV/AIDS-infected individuals than observed in the general population.[27] Reduced ability to perform work related activities and decreased productivity erodes the financial stability of the family. Evidence of severe disparity among the infected population is well document in the literature.[15,28,29] African Americans who make up 13% of the total US population actually make up 49% of the new HIV-infected population, an increase from 25% in the past two decades.[34] Reduction in income, deterioration of physical and mental health, regular incidences of discrimination, lack of access to healthcare resources and a constant fear of parental loss makes the children vulnerable to numerous health related consequences. Current health investments of a child are a strong determinant of the child's future healthcare needs. It is pertinent to understand the impact of the disease (HIV) on the health and healthcare utilization of the children living in HIV-infected families. Lack of adequate public policy undermines the attention required by the growing vulnerable population.

1.3 Research Question

What is the impact of parent(s) HIV seropositive status on the health healthcare access, healthcare utilization and health outcomes of their children? This study aims to investigate the healthcare access, healthcare utilization, and health outcomes of uninfected children living with their HIV seropositive parents.

1.4 Purpose of the Study

- The primary purpose of this research was to determine whether the health outcomes of uninfected children living with their HIV seropositive parent(s) differed significantly from the health outcomes of uninfected children living with their HIV seronegative parent(s).
- The secondary purpose included investigating differences in the healthcare utilization and access to healthcare between uninfected children living with HIV seropositive and seronegative parent(s).

1.5 Conceptual Model

The conceptual model for this study was based upon two pivotal models found in the healthcare study literature - The Andersen's Healthcare Utilization Behavioral Model[30] and the Grossman's concept of Human Capital & Demand for Health Model.[31]

1.5.1 Andersen's Behavioral Model for Health Service Utilization

Healthcare utilization has been addressed in many studies in the past couple of decades. One of the pivotal studies explaining the determinants of healthcare utilization has been the conceptual model proposed by Ronald Anderson in 1968.[32] At that time the model explained the utilization of healthcare services taking 'family' as a measure of study since the consumption of these services by any individual was a function of the family's demographic, social and economic parameters. However, the rising complexity of defining and measuring family attributes that determined individual's behavior towards use of healthcare services lead to redesigning of the model based on the 'individual' as the unit of analysis and incorporating additional variables into the original model.[33-36]

According to this revised model the healthcare utilization outcomes of an individual was determined by various factors which can be categorized into three major areas: Population characteristics, Environment, and Health behavior (Figure 1-1).

1.5.1.1 Population Characteristics

The population characteristics can be further grouped into predisposing, enabling and need factors. The predisposing factors are the individual's demographic, socio-structural and attitudinal-belief variables. The demographic variables such as age and gender determine the likelihood that the individual would require a service. The socio-structural variables define the status of the individual in the society as a determinant of healthcare utilization and include factors such as ethnicity, race, occupation and level of education. Individual's health beliefs about the healthcare environment and health services drive the need for health and healthcare services, and constitute the attitudinal-belief component of the predisposing factors. In order for an individual to utilize these services, apart from the desire to consume, is its availability and accessibility. The factors that facilitate the individual to consume the desired quantity of services, that is make it available and access it, are termed as 'enabling factors. These enabling factors can be at a community or personal level and includes variables such as income, health insurance status, regular source of care, access to prescription drugs, adequate transportation, community and social support, etc. Though the predisposing factors and the enabling factors drive the individual's degree of healthcare service utilization the 'need' factor regulates the initiation of the individual's requirement of healthcare services. It comprises of the biologically driven variables such as individual's perceived general and functional

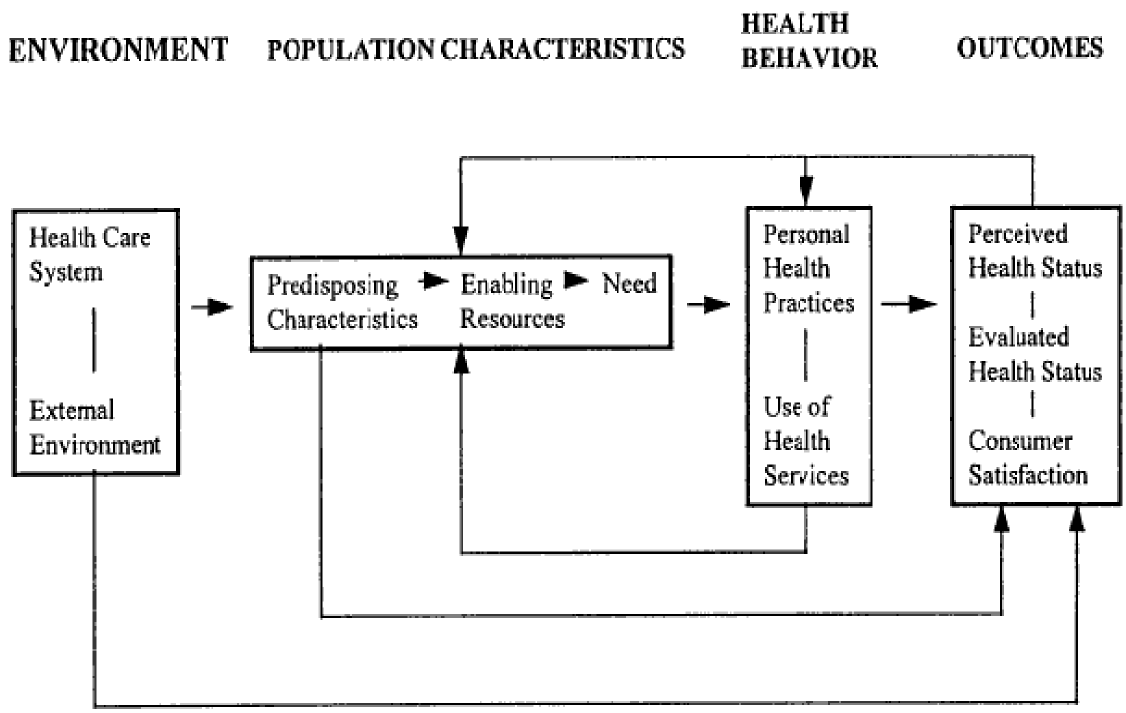


Figure 1-1: Andersen Healthcare Utilization Behavioral Model
(Reprinted with permission from American Sociological Association. Andersen, RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* 1995;36:1-10.)[30]

self-health status, severity of disease and symptoms, and the perceived need to seek for medical attention.

1.5.1.2 Environment

The importance of healthcare system and policies became crucial in driving healthcare utilization both at micro and macro level. This component was developed and added to the original model by Aday et al.[33,36] Factors such as the type of healthcare system, resources and their organizations in the healthcare system, national health and educational policies, etc, represent the environmental factors.

1.5.1.3 Health Behavior

Increase in the health awareness among the population and self-education health initiatives by individuals are newly emerging determinant of healthcare services in recent years. Factors such as the individuals effort to improve and maintain its own health status, personal health practices such as diet, exercise and self care, constitute the health behavior variable.

1.5.2 Grossman's Human Capital and Demand for Health Model

Michael Grossman, in 1972, conceptualized "good health" as a human capital and developed a model for the demand for "good health" as a product of human consumption. In his concept Grossman proposed that individuals not only consume services that add to their health but also produce "good health" using the resources available in the form of healthcare and medical services. According to Grossman, every individual is born with an initial stock of health and this stock depreciates with time. The concept further reinstates that individuals can increase their health stock by investing in the production of their "good health". These investments can be in the form of human capital (health and education) and/or as market goods to enhance their health outcomes in both, market (work) as well as in the non-market (household) regions.[31] So every human being produces "good health" with the help of healthcare services/products and their own time. The amount of time invested and quantity of healthcare services consumed depends upon the individual's stock of health. One more key variable of interest expressed by Grossman that drives the production (market and non-market) is the individual's amount of knowledge. Knowledge increases the person's productivity with respect to time and hence augments the rate of production of "good health". At the same time, knowledge also increases the person's market value and hence strengthens the individual's financial ability to consume more healthcare services. The time spent on production of "good health" is a function of the marginal utility derived from this commodity. Individuals keep producing "good health" only till the point where the marginal utility gained from it equals the marginal utility gained from using the same time in other non-health producing activities such as work or leisure. Hence individuals with a good health stock (healthy) have a lower marginal utility in producing further health in comparison to the individuals with a lower health stock (sick). And this is the reason why sick individuals tend to have a higher utilization of healthcare services in comparison to healthy ones. And since healthcare services are consumed to produce "good health" hence lower consumption may lead to lower production, and is identified as inadequate investment in health. Individual with a high degree of knowledge is more efficient in producing "good health" and can make right health decisions for themselves and their families leading to a healthy life. In his concept Grossman identified 'education' as a key determinant in the production of health.[10,37]

1.5.2.1 Individual as a Producer of "Good Health"

Grossman's model can be represented by the following mathematical equations. Since individuals derive its utility from their current health stock 'H_t' and from the other commodities Z_t, the equation for the derived utility 'U_t' in period 't' is given by,

$$U_t = u(H_t, Z_t)$$

This concept assumes that the health stock of every individual depreciates with time and this depreciation can be recovered with further production of health, hence the "good health" created over time is the difference between the production of additional health stock 'I_t' and the depletion of current stock '$\delta_t H_t$' and is given by the following equation:

$$\delta H_t / \delta t = I_t - \delta_t H_t$$

The individual creates total health investment 'I_t', and consumes other commodities, 'Z_t', using the following inputs,

$$I_t = (M_t, h_{t,H}; E_{t,H}), \text{ and}$$

$$Z_t = (X_t, h_{t,Z}; E_{t,Z}),$$

where M_t and Z_t are market goods, and $h_{t,H}$ and $h_{t,Z}$ are the time periods of individuals consumed in the production of "good health" and other commodities, respectively. $E_{t,H}$ and $E_{t,Z}$ are efficiency parameters.

1.5.2.2 Family as a Producer of "Good Health"

An extension of the Grossman model, which actually focused on individual's health was derived using family as a unit of measure by Lena Jacobson.[9] In this model a family comprising of husband, wife and a child was considered as a unit in production "good health."[9] The mathematical representation of the utility derived by Grossman was modified to include the family members as below,

$$U_t = u(H_m, H_f, H_c, Z_t),$$

where, H_m, H_f and H_c are the health of the male parent (father), female parent (mother) and that of the child, respectively.

In the family, as a producer of health of each member, the parents not only produce health for themselves but are also involved in the process of their child's production of health. This includes using their time, healthcare resources and knowledge as input variables in their child's production of health. Hence parent's individual health stock, commonly known as health status, and production efficiency or knowledge, commonly known as level of education, are two pivotal determinants of the child's production of "good health."

In this framework the child has been taken as the unit of measure but since the child is an integral part of the family and most the health related decisions are taken by the parents on behalf of the child hence family (parents) was identified as a key variable in the conceptual model. The health outcome, which is a function of the health status of a child, is dependent on the amount of health investments done by their parents. These health investments are in the form of utilization of healthcare and medical services, diet, environment the child lives in, time, and attention shared by the parents with the child, in order to generate "good health" for the child.

The efficiency of the health production is greatly dependent on the age and education level of the parents and hence is termed as the 'Efficiency parameters.' Efficiency decreases with the increase in age and increases with increase in the level of education of the parents. Younger parents are healthier and have higher health stock hence can invest more to produce "good health" for themselves and for their children in comparison to older parents. Increase in level of education not only increases the market productivity value of the parents leading to increase in their income but also increases the quality of health related choices made by the parents for themselves and for their children. The healthcare utilization of the child is determined by the parent's health status, child's predisposing factors (age, gender, ethnicity, race, education and parent's genetic contribution), child's need factors (presence of disease and any special health needs), and the child's enabling factors (family income, regular source of care, access to health and prescription insurance, and access to transportation). Similarly, the parent's health status is determined by their own health inputs which are a function of their predisposing, enabling and need factors.

If we assume that the child is completely dependent on their parents for their health investment then the child's production of health is primarily the function of the parent's health status and the parent's healthcare utilization, that is parent's predisposing, enabling and need factors. Hence, if the parent has a low stock of health then it will have a negative impact on the amount of health inputs invested in the child and will hamper adequate production of health in the child. So the child will have a lower health status and hence have compromised health outcomes. Low health outcomes make the child medically compromised and hence utilizes medical services like medicines, hospitalization or emergency room visits, in order to compensate for the compromised health stock. Good health results in better production of "good health" and hence lower use of prescription drugs, lower rate of hospitalization and emergency room visits.

In this study the hypothesis states that since the parent is suffering from HIV/AIDS infection hence they have a compromised health status. This impact the health investments made in their child leading to low health stock in comparison to the children of seronegative parents. Low health stock makes the child sicker and requires greater medical attention. This leads to higher utilization of healthcare and medical services in comparison to the uninfected children of seronegative parents.

1.5.3 Parent-Child Healthcare Behavior Model

Based on the concepts of the Anderson Model and the Grossman Model this study aimed to develop a combined model that would include the health status of the parent as a crucial predictor of the child's healthcare investments and health outcomes. A 'Parent-Child Healthcare Behavior Model' was developed that included all the variables and predictors identified by Anderson's Model and Grossman's Model (Figure 1-2).

1.6 Specific Aims and Hypotheses

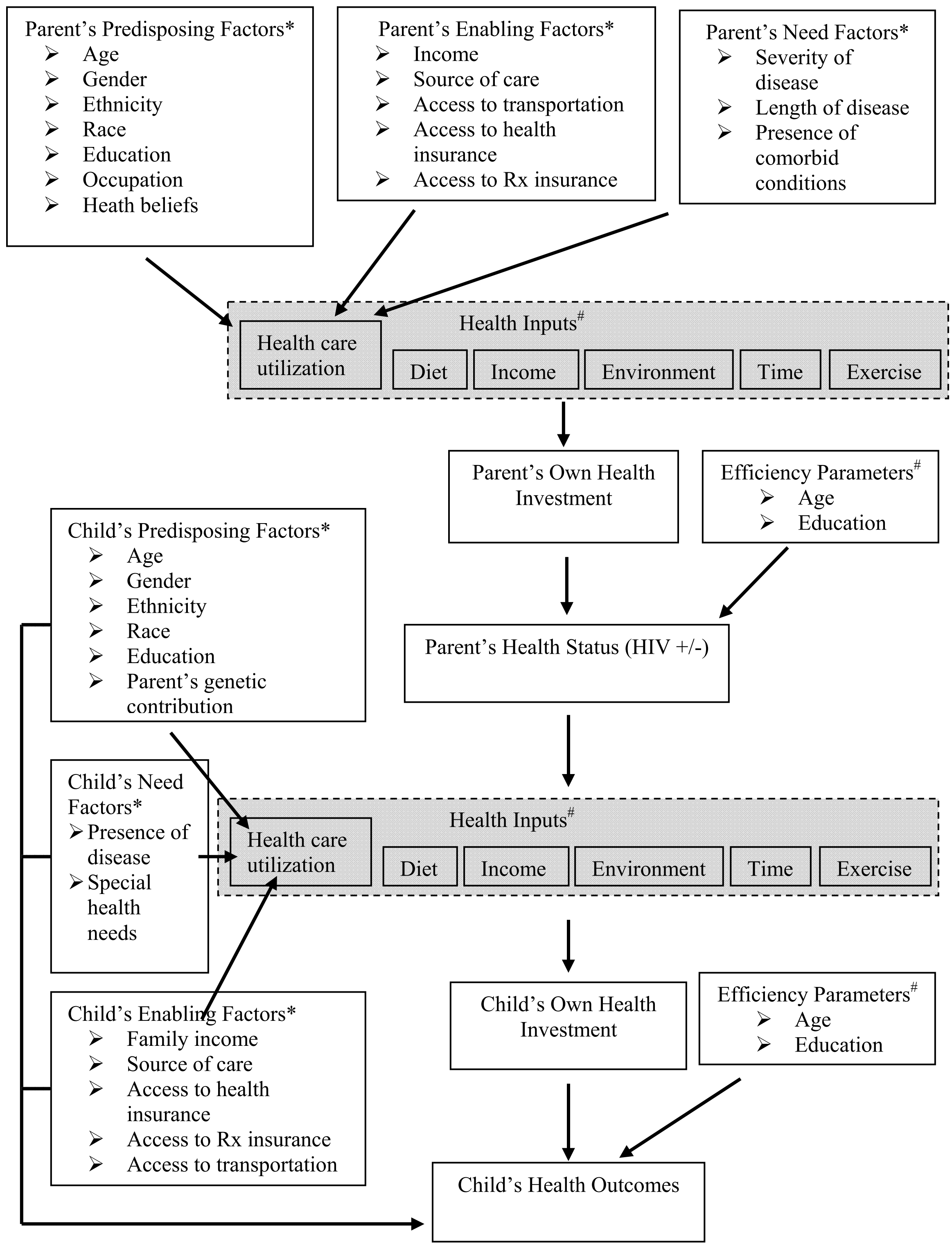
The study aims and the related hypotheses were as follows:

- ***Aim 1**: To determine whether HIV seronegative children living with HIV seropositive parent(s) have lower healthcare access in comparison to the HIV seronegative children living with HIV seronegative parent(s).*

  - *Hypothesis 1:* Lower proportion of children living with HIV seropositive parents have a health insurance compared to children living with HIV seronegative parent(s).
  - *Hypothesis 2:* Lower proportion of children living with HIV seropositive parents have a regular source of care compared to children living with HIV seronegative parent(s).
  - *Hypothesis 3:* Lower proportion of children living with HIV seropositive parents have a prescription drug insurance compared to children living with HIV seronegative parent(s).
  - *Hypothesis 4:* Higher proportion of children living with HIV seropositive parents take more than 15 minutes to get to a healthcare provider compared to children living with HIV seronegative parent(s).
  - *Hypothesis 5:* Higher proportion of children living with HIV seropositive parents indicate having difficulty in getting to a healthcare provider compared to children living with HIV seronegative parent(s).

Figure 1-2: Parent-Child Healthcare Behavior Model

Combining factors from *Andersen Healthcare Utilization Behavioral Model (Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* 1995;36:1-10)[30] and #Grossman Human Capital Model (Grossman M. The demand for health: a theoritical and emperical investigation. *NBER Occasional Paper 119, New York.* 1972.)[31]


Parent's Predisposing Factors*
Age
Gender
Ethnicity
Race
Education
Occupation
Heath beliefs
Parent's Enabling Factors*
Income
Source of care
Access to transportation
Access to health insurance
Access to Rx insurance
Parent's Need Factors*
Severity of disease
Length of disease
Presence of comorbid conditions
Health Inputs#
Health care utilization
Diet
Income
Environment
Time
Exercise
Parent's Own Health Investment
Efficiency Parameters#
Age
Education
Parent's Health Status (HIV +/-)
Child's Predisposing Factors*
Age
Gender
Ethnicity
Race
Education
Parent's genetic contribution
Child's Need Factors*
Presence of disease
Special health needs
Health Inputs#
Health care utilization
Diet
Income
Environment
Time
Exercise
Child's Enabling Factors*
Family income
Source of care
Access to health insurance
Access to Rx insurance
Access to transportation
Child's Own Health Investment
Efficiency Parameters#
Age
Education
Child's Health Outcomes

- ***Aim 2**: To determine if HIV seronegative children living with HIV seropositive parents have higher healthcare utilization in comparison to the HIV seronegative children living with HIV seronegative parent(s).*

    - *Hypothesis 6***:** Children of HIV seropositive parents have higher likelihood for a doctor's visits compared to children of HIV seronegative parent(s).
    - *Hypothesis 7:* Children of HIV seropositive parents have higher likelihood for a hospital visit compared to children of HIV seronegative parent(s).
    - *Hypothesis 8:* Children of HIV seropositive parents have higher likelihood for an emergency room visit compared to children of HIV seronegative parent(s).

- ***Aim 3**: To determine the healthcare outcomes of the HIV seronegative children living with HIV seropositive parents in comparison to HIV seronegative children living with HIV seronegative parent(s).*

    - *Hypothesis 9***:** Children of HIV seropositive parents have higher likelihood to have a school/daycare day missed due to ill health compared to children of HIV seronegative parent(s).
    - *Hypothesis 10:* Children of seropositive parents have a higher likelihood to be overweight compared to children of HIV seronegative parent(s).
    - *Hypothesis 11:* Children of seropositive parents have a higher likelihood of being currently on a prescription medication for any health condition compared to children of HIV seronegative parent(s).
    - *Hypothesis 12:* Children of seropositive parents have a higher likelihood to being currently on a prescription medication for mental health condition compared to children of HIV seronegative parent(s).

1.7 Terms and Definitions

- HIV — Human Immunodeficiency Virus (HIV) is a surveillance definition of a disease based on signs, symptoms, infections, and cancers associated with the deficiency of the immune system that stems from infection with HIV.[46] It is a type of virus known as 'retrovirus' which infects the cells of the body's immune system, mainly the CD4 positive T cells and the macrophages thereby impairing the cellular immune system of the body.
- AIDS — Acquired Immunodeficiency Syndrome (AIDS) applies to the most advanced stages of HIV infection, defined by the occurrence of any of more than 20 opportunistic infections or HIV-related cancers. In addition, the UNAIDS and CDC defines AIDS on the basis of a CD4 positive T cell count of less than 200 per mm^3 of blood.[38,39]
- HIV Seropositive — Patients who are diagnosed as HIV positive using an official serology test. In a non-HIV-infected person the CD4 count ranges from 700 – 1000 in a single drop of blood. A HIV-infected person is said to be normal if the CD4 count is above 500 and as it drops below 200 the person is classified as HIV/AIDS patient.

- HIV Seronegative — Patients who have a diagnosis of HIV negative or have no previous record for a medical diagnosis of HIV/AIDS.
- Uninfected Children — Children who have a diagnosis of HIV negative or have no previous record for a medical diagnosis of HIV/AIDS, and are currently living with their parent(s).
- Primary Group — Uninfected children of HIV seropositive parent(s) who are currently residing with their HIV-infected parent(s).
- Comparative Group — Uninfected children of HIV seronegative parent(s) who are currently residing with their parent(s).

1.8 Assumptions

- Since the study included interviews of individuals, it was assumed that the study participants were truthful and as accurate as possible in responding to the study questionnaire.
- It was assumed that the respondents had adequate and complete knowledge about their children to answer the questions pertaining to them.
- The investigator was allowed to access the medical records and reports of the study participants by the physician after receiving proper authorization from the study participants.

1.9 Limitations

In this study, convenient sampling technique was used to identify the study population. This population may lack generalizability to represent the complete HIV / AIDS population in the United States; however this study aimed to generate pertinent information that will assist in addressing similar issues evident in the general population. The study results are also a stepping stone for future research. Much of the health status of the child was assessed by information gathered from the parent. This may not have reflected the exact health status of the child. However, the investigator expected to collect enough information to reach certain logical conclusions. HIV negative parents were defined as those who did not have a prior diagnosis of a HIV infection by a physician. Literature cites that almost 25% of the HIV-infected individuals are not aware of their HIV positive status.[39] The absence of a confirmatory serological test to identify HIV negative parents may limit the study results. Since the data collected was based on self-reported events, therefore the results may also be subjected to recall bias.

1.10 Relevance

The economic impact of HIV/AIDS has been recognized and studied in depth and it is no surprise that poverty seems to be the most significant variable impacting the spread of this disease. Lack of adequate knowledge coupled with limited education and health related information leads to improper decision making by the parents and exposes their family members, especially children, to a plethora of health related ailments. This study would provide some insight as to the health status of the HIV-affected children and whether these children need immediate attention.

Understanding and identifying the healthcare needs of this at-risk population will assist in designing health policies both at the micro as well as at the macro level. This study will be a resource for policy makers, social workers, researchers, physicians, healthcare professional and to the society as a whole. The results of this study will aid the healthcare professionals in identifying and acknowledging the facts and design interventions needed. This study will also provide valuable information to social workers and public health workers dealing with the HIV-affected families at the micro level to identify the healthcare needs of the children in these families.

Finally, this research adds to the body of literature and is a resource for future researchers and projects. This study generated numerous research questions and hypothesis that will promulgate better understanding of the impact of parent's HIV status on their uninfected children.

1.11 Organization of the Study

The complete study has been organized into five chapters. Chapter 1 provides the introduction and the purpose of the study. Chapter 2 comprises a review of current literature and provides an overview of the body of research studies conducted on the prevalence, spread and the socio-economic impact of HIV/AIDS as a disease on the children of infected parents. In the chapter 3, a detailed description of the research design, study population, methodology, study variables, study instruments, data collection method and the analysis techniques are presented. This section also provides insight on the various economic theories and concepts relating to health and healthcare in terms of investment, access, utilization and outcomes. Chapter 4 highlights the study results and the analysis of the data. Chapter 5 includes the interpretations and conclusions deduced from the analysis of the data, provide health policy recommendations, and identify future research topics.

CHAPTER 2: REVIEW OF LITERATURE

The purpose of this study was to analyze the variation in the healthcare utilization and healthcare access of the uninfected children staying with their HIV seropositive parent(s) compared to those staying with their HIV seronegative parent(s). The study also proposed a model that will illustrate the impact of parent's health HIV status on the healthcare utilization and health outcomes of their children. The review of the literature for this research study has been divided in to two major sections. The first section highlights various issues relating to parenthood among HIV/AIDS-infected individuals and the related studies. And the second section presents a synopsis of the studies investigating the impact of HIV/AIDS on the uninfected children/families of infected individuals. A critical review of literature on the impact of parent's illness on the healthcare utilization of the child has also been discussed in the final section.

As this study deals with the HIV disease it is pertinent to provide the readers with adequate information on the history, etiology and the prevalence of the virus in the human population. This information has been summarized in the Appendix A of the dissertation.

2.1 Section I: Impact on HIV/AIDS-Infected Individuals

2.1.1 Non-Disclosure of HIV Status among HIV-Infected Individuals

A desire to have a child is a cultural norm and a socially accepted phenomenon in the United States irrespective of the HIV status of the individual.[40,41] Despite clinical reasons that hinder parenthood, lack of desire for children is often viewed as a serious violation of this cultural norm.[42] The HIV/AIDS virus has been a socially stigmatized disease and is the reason for delaying treatment and accessing medical care.[43,44] Disclosure of the HIV status to the sexual partner is also low, despite the fact that concealing the fact to the other partner before a sexual act is a criminal offense in almost 31 states in the United States.[45] A study by Ciccarone et al. reported significantly high rates of non-disclosure of the HIV status to the sexual partner among HIV-infected individuals.[46] The study also reported that the non-disclosure rates were higher among gay or bisexual men (42%), followed by heterosexual men (19%) and women (17%). Across all the groups nearly 13% of the sexual encounters involved unprotected anal or vaginal sex.[46] Non-disclosure and prevalence of unprotected sex among the infected population augment the possibility of the pregnancy among HIV-infected women.

A meta-analysis of factors influencing disclosure of the HIV status among HIV-infected males showed that 68% to 88% of the primary sex partner being aware of the HIV status of the infected male where as only 25%-58% of the partner other than the primary partner was aware of the HIV status. The likelihood of disclosure reduced significantly with increase in the number of partners having sex with the infected individual.[47]

Disclosure of the HIV status by infected parents to their children (5-17 years) has been estimated to be around 44% in a study done on a nationally representative sample. Parents with high income, high CD4 counts, greater social isolation and those with younger children were less likely to disclose their HIV positive status to their children than other infected individuals. Most parents cited unwanted emotional consequences (67%), fear that child may disclose to other people (36%), and lack of knowledge on how to disclose (28%) as prime reasons for their decision to not disclosure their HIV positive status to their children.[48]

2.1.2 Pregnancy among HIV-Infected Mothers

Trends in pregnancy among HIV mothers in the United States from 1990 to 1994 was studied by Chu et al. (1996) and then later from 1992 through 2001 by Blair et al. (2004).[49,50] Chu et al. reported that 14% of the infected women were pregnant whereas the study by Blair reported it to be 16%. The HAART guidelines and recommendations[51] were effectively used in clinical practice since 1996 and therefore the impact of the HAART treatment on the pregnancy rates among HIV-infected women was evidently visible. Similar results were observed among perinatally HIV-infected children. In comparison to the children born in between 1980-1995 the birth cohort of 1996-1997 (Hazard ratio: 0.39, 95% CI: 0.15-0.96) and 1996-1997 (Hazard ratio: 0.65, 95% CI: 0.45-0.95) had higher survival rates unadjusted for maternal antiretroviral treatment during pregnancy and clinical condition at time of delivery, gestational age, and birth weight.[52]

Blair et al., 2004, based findings on the analysis of HIV-infected women aged 15-44 years participating in the Adult/Adolescent Spectrum of HIV Disease Project Study. On an average 5.5% of the HIV-infected women became pregnant each year. The study reported that women aged 15 to 24 years (RR: 9.2, 95% CI: 7.4-11.3) and between 25 to 34 years (RR: 4.0, 95% CI: 3.3-4.9) had a higher likelihood to become pregnant compared to women aged 35 to 44 years. Women undergoing HAART treatment had higher rates of pregnancy (RR: 1.3, 95% CI: 1.0-1.6) than those who were on other regimens of ARVs.

The risk of vertical transmission (mother to child) has reduced tremendously over the years. This has been the single most reason for the increase in the number of children born to HIV-infected individuals. With the advent of the HAART treatment has further augmented the likelihood of the HIV-infected parent to be pregnant. Studies suggest less than 2% of the children get infected if the mother had started the HIV treatment early in the pregnancy, 12-13% of the children get infected if the mother had not started the treatment until labor, delivery or after birth, and 25% of the children get infected if their mothers did not receive any preventive treatment.[53] It has also been reported that HIV-infected women who become pregnant even after the knowledge of their HIV status are generally younger, less educated, have stayed longer with their HIV infection, had more previous history of pregnancies, miscarriages and abortion than those infected women who do not.[54]

Researchers have associated the desire to have child as a significant predictor in the pregnancy decision making process in addition to the fear of transmitting the infection to their child, and personal health related concerns.[55,56] Other external explanatory variables that influence pregnancy decisions among HIV-infected women found in the literature are husband and sex partner,[54] attitudes of family members,[4] medical provider[4] and significant others with HIV.[4,54,57]

2.1.3 Child Bearing Desires among HIV-Infected Individuals

Chen et al. (2001) interviewed 1,421 HIV-infected adults who were a part of the HIV Cost and Services Utilization Study to investigate the relationship between the socio-demographic and health factors that influence child bearing desired among the HIV-infected population in the United States.[58] The study reported that almost 28% of the HIV-infected population, 28% among infected men and 29% among infected women, expressed their desire to have a child in future. The proportion of women desiring a child in the future was higher (69%) compared to those among men (59%). The study also found that HIV-infected women desiring a child were younger (27% were >30 yrs versus 5%, p=0.0014), had fewer children (37% had no children versus 11%, p=0.0020), less likely to be married (19% married versus 29%, p<0.0001) and had scored higher on the overall health (80.5% versus 70.2%, p=0.0002) than their counterparts who declined to have a child in future. HIV-infected women who already have a child were less likely to expect children in future than the HIV-infected women who have no children. The desire to have child among black non-Hispanics (51%) HIV-infected individuals were higher than those expressed by white non-Hispanics (32%).

2.2 Section II: Impact on HIV/AIDS-Affected Individuals

2.2.1 Growing Population of Children Living in HIV-Infected Households

It is estimated that around 62,800 HIV-infected families in the United States have children living with them. The number of these children less than 18 years of age in 2000 was estimated to be 120,300 children.[1] This number has been growing due to early HIV detection and increasing life expectancy of HIV-infected individuals. Rising proportion of women among the HIV-infected population, especially in the child bearing age, has also been attributed as one of the reason. Effective treatment decreases the transmission of the infection from mother to child resulting in decreased incidences of vertically transmitted HIV infection to a large extent.[59,60]

Schuster et al. (2000), studied the number, characteristic, and the living situation of children of HIV-infected adults.[1] In this study the researchers used the HIV Cost and Health Utilization Study database. This database was created from a multistage national probability sampling that selected HIV-infected adults through random sampling who had at least one healthcare visit at a facility other than a military, prison, or emergency department facility within a 2-month population definition period in early 1996.[61] The study was conducted in 1996 and 2864 HIV-infected adults were interviewed for information related to their socio-demographic information, current physical and mental health status, number of offspring, HIV status of their offspring and primary caregiver of the offspring. Out of the 2864 respondents interviews, 2803 (98%) had completed their survey. From these reports of 3138 offspring were collected and out these 1644 reports were of children younger than 18 years. Sample weights were used to represent the data to the entire HIV-infected population. This study found that 28% of the HIV-infected adults (62,800) have children, aged less than 18 years and 52% of these children currently live with their infected parent(s). Women have a higher likelihood of having a child (60% vs 18%, $p<.001$). Among the parent living with at least one of their children, 76% were women. Almost 26% of the HIV-infected women younger than 30 years reported to have conceived after being diagnosed for the infection. 21% of these infected parent reported to have been hospitalized in the past 6 months, 18% reported to have required home health care in the past 6 months, 45% had mental health needs, 10% showed probable signs of drug dependence and 10% reported to have received a drug or alcohol treatment in the past 6 months. Out of the total 3138 children considered in this study, 49% had a HIV test prior to the survey and among these 4% of the children were tested positive. Since 3% of the respondents were dropped due to incomplete responses hence the study findings may be underestimating the actual numbers. More than 25% of the HIV population is unaware of the disease and this can significantly add to the current estimate of the number of children affected by the disease.[39]

2.2.2 Impact of Parent's Illness on Children

Parents, by nature, are responsible for governing and nurturing their children. Therefore, numerous factors related to the parents have an impact on the child's health, healthcare access and healthcare resource utilization. Parents have always acted as the 'gatekeepers' for their child's healthcare access and utilization. Parent's emotional functioning and perception about their child's health, especially those of the mothers, are significant predictors of child's healthcare utilization.[62] Also parent's health condition, health beliefs and health literacy have been positively associated with the child's access and utilization of healthcare resources.

Altman et al. used the 1987 National Medical Expenditure Survey (now called as Medical Expenditure Panel Survey) to investigate the healthcare utilization of family members of individuals with disability and found that the mean medical expenditure and the number of physician visits were higher for members having a disabled family member compared to members without a disabled family member.[63] Upon adjusting for various demographic and socioeconomic variables showed that children living in a family with a disabled members have a 7.5 percentage points greater probability of having a physician visit (p>0.1).

Lipstein et al. (2009) used the National Health Interview Survey (NHIS) to study the impact of the parent's health status on the health outcomes and healthcare utilization in children with asthma.[64] The parent's health status was measured by the presence or absence of at least one chronic illness (coronary heart disease or any other heart disease, emphysema, asthma, diabetes, kidney dysfunction, any kind of liver related disease, arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia, or if the parents reported some limitations of activity because of chronic illness). The study concluded that no significant differences (p=0.47) in the number of emergency visits or the outpatient visits between children of parents with and without chronic illness. However, significant differences were observed in the average number of school days missed in a year for children of parents with chronic illness versus children of parents without chronic illness (6.6 versus 4.9, p=<0.01). Also 74.4% of the children of parents without chronic disease reported to have excellent/good health compared to 62.3% of the children of parent having a chronic disease (p=0.01).

A 10 year follow-up study of children reported a significant association between the parental depression status and the risk for medical problems and hospitalization among children.[65] Similarly, Weissman et al. (2006) followed the offspring of depressed and non-depressed parents for a period of 20 years to explore the magnitude of the risk it poised on their children's health.[66] Weissman et al. found a threefold increase in the incidents of anxiety disorders, major depression, and substance abuse among children of depressed parents compared to the children of non-depressed parents. The study also observed emergence of increased rates of medical problems and mortality in the offspring of depressed parents. These risks were higher in female child compared to male child. Flynn et al. (2004) studied the children (less than 7 years of age) visiting the pediatric emergency department and found that 31% of the mothers were screened positive for risk of depression and 78% among those were not currently receiving any form of treatment for depression.[67] Higher emergency department visits (OR: 2.91; 95% CI: 1.01-8.40) were observed among children of mothers with depression, and that these children also were more likely to miss a doctor's appointment (OR: 2.90; 95% CI: 1.18-8.70), compared to children with non-depressed mothers.

Visser et al. (2005) focused their study on the emotional and behavioral functions of children living with parents having cancer.[68] They measured the emotional and behavioral functioning of the children who had both or either of their parents diagnosed for cancer using the Child Behavior Checklist (CBCL) and the Youth Self Report (YSR) instruments.[69,70] The study observed age and gender of the child as significant factor in determining the magnitude of the impact of parent's illness on the child. Male children aged 4-11 years were found to have higher emotional problems (7.1% versus 4.8%, p≤0.05) compared to group of children of parents without cancer. Adolescent (12-18 years) daughters were having higher proportions of emotional and behavioral problems compared to the adolescent sons among parents suffering from cancer (7.2% versus 5.4%, p≤0.001). Higher proportions of behavioral problems were observed among daughter and sons when the parent suffering from cancer was the father (p≤0.01).

A study by Olfson et al. (2003) reviewed in to the association of the presence of depression among parents and the child's mental health problems and their healthcare utilization.[71] They used the Medical Expenditure Panel Survey (MEPS) 1997 data and concluded that children of parents diagnosed with depression are twice as likely (95% CI: 1.4-2.9) as the children of parents without depression to have a psychological problem, and 2.8 times (95% CI: 1.9-4.2) more likely to use mental health services. This study found no differences (39% versus 36.6%, p value=0.63) in the occurrence of psychological problems in children of parents receiving treatment for their depression and parents not receiving treatment, however the difference in the utilization of mental health services were significant (15.1% versus 4.0%, p=<0.0001) among children whose parents received treatment for depression. Olfon et al. (2003) also found that among the parental depression group, 77% of parent having depression were mothers of the children.

Recent studies based on the National Maternal and Infant Health Survey (NMIHS) data showed that mothers suffering from depression exhibit lower use of injury prevention strategies such as proper handling of children, proper use of car seats, safe guarding electrical outlets in home, and safe keeping of poisonous or hazardous substance in home.[72,73] Using nationally representative data from the National Institute of Child Health and Human Development (NICHD) Study of Early Child Care, Schwebel et al. (2008) examined the relationship between chronic maternal depression and child injury over a period of birth to 3 years and from 3 year to Grade I.[74] The study reported that the children from birth to age 3 years of severely depressed mothers had an injury rate three times higher than the children whose mothers did not have depression. The adjusted univariate model identified severe maternal depression as a significant predictor of child injury (t=4.52; p<0.01; 95% CI: 0.61-1.54).

2.2.3 Defensive Mothering among HIV-Infected Mothers

Motherhood imbibes a feeling of pride, social recognition, source of love in a woman and ensured legacy for future.[75,76] However this concept among HIV-infected mothers also include fear, isolation and abuse. Some researchers have identified mothering among HIV-infected women to be more of survival rather than source of self esteem and social identity.[77-81] Ingram and Hutchinson (1999) studied the mothering experience of HIV-infected women.[17] The investigators conducted focused interviews of 18 HIV positive mothers aged between 18-44 years. The study took a qualitative approach and used the grounded theory to analyze the study findings. The researchers found a high degree of fear and uncertainty among the mothers in regards to the future of their children, in terms of health and social acceptability. Three fundamental themes were observed: preventing the spread of HIV and stigma, preparing the children for a motherless future, and protecting themselves through thought control. Mother felt the need to over protect their children and took more care of their children. No doubt, this sense of defensive mothering among HIV-infected mothers did help them to combat the threats associated with the disease, however such an attitude may also lead to over utilization of healthcare resources. This particular phenomenon was also reported by Gulhati and Minty (1998). They studied the association between the parental illness and health attitudes, and the referrals of children to medical specialists. The study findings suggested that mothers with a medical and psychiatric history perceived the medical condition of their children to be more adverse, made higher referrals to specialists, and expressed less willingness to accept medical reassurances. Numerous studies have reported the relationship between factors and resilience among children in HIV- infected families. Dutra et al. (2000) found significant correlation between resilience in children and parent-child relationship, parental monitoring and parental structure. Resilience was found to increase coping skills and self efficacy among children living in HIV-infected families.[82]

2.2.4 Impact of Parent's HIV Status on Children

Depleting health of the infected individual depletes the financial, social and emotional resources of the family and this has a detrimental short and long term impacts on the children living within the family. Poverty is one of the major factor that the HIV-infected families go through.[83] Deteriorating health of the earning member not only decreases individual's earning capacity but also increases the cost of treatment. Social stigma attached to the disease weakens the social support system for the entire family. Death of the HIV-infected parent does not put an end to plight of the children. Early loss of a parent, sometimes both parents, exposes the child to loss of parental love, grief, hardship, insecurity and lack of value based upbringing.

2.2.4.1 Child's Physical Health

A study conducted by Starc et al. (1999), reported unexpected non-HIV-related deaths in children born to mothers with HIV infection.[13] This study reviewed the 121 deaths among the 805 children enrolled in the Pediatric Pulmonary and Cardiac Complications of Vertically Transmitted HIV Infection study. This study suggested that the infants born to HIV-infected mothers have a high risk for traumatic and accidental deaths (standardized mortality ratio: 7.35; 95% CI: 2.0-18.7). And that the risk is highest during the first few months of life.

Ross et al. (1995) studied the impact of the maternal HIV infection and drug use during pregnancy on the growth of the infected child.[19] The study focused on the weight and height of the child in their first 3 years. The study participants were identified from the healthcare setting in Edinburg, Scotland, between 1983 and 1992. Two hundred and fifty three uninfected children born to 43 HIV-infected mothers with a history of drug use were retrospectively followed for a period of 3 years from the birth of the child. For each child two controls were matched for parity, age (within 5 years), year of birth, smoking status of mother, hospital, delivery complications (twins or if any other) and ethnic group. The height and weight of the child was taken from the child health surveillance records measured during the predefined window periods 5-12 weeks, 7-18 months, and 2-4 years. The sex adjusted weights and heights were used to calculate the body mass index (BMI) using the standard formula (weight in kg/square of height in meters). The study concluded that there was no significant affects of the HIV status on the growth of the child upon 3 years. Though children of mothers who smoked has low birth weight at birth but this difference were negligible by 3 years. The major drawback of this study was in the sample selection as it only included children who made to their third year and could have excluded those children deceased before the 3 year time period.

A similar study done among the European population compared the growth rates of uninfected children versus infected children born to HIV-infected mothers. The children were followed from the birth to 10 years of age.[20] The study showed normal growth among the uninfected children but the infected children had a lower height and weight, especially after the 2nd and the 4th year, in comparison to the uninfected children. The general HIV population in Europe is less socio-economically disadvantaged than the HIV-infected population in the United States and also the healthcare system in Europe is different in terms of reimbursement structure, hence the studies done on European population may not represent the population in the United States. Also disparity in health outcomes is larger in the United States in comparison to the other developed European countries.[84,85]

2.2.4.2 *Child's Mental Health*

The mental health needs of children living in HIV-infected families have been studied in depth. With increase in the survival expectancy the HIV-infected parent(s) are living longer with the disease. This longer association with the disease results in numerous psychological disorders among the infected parents. Recent studies have found alarming proportions of psychological symptoms among the infected population. Bing et al. (2001) conducted a study that estimated the national prevalence of psychiatric disorders (major depression, dysthymia, generalized anxiety disorders and panic attacks) and use of illicit drugs among the HIV-infected adults in the United States.[86] The HIV Cost and Service Utilization Study (HCSUS) was used and a nationally representative sample comprising of 2864 HIV-infected adults receiving care was sampled. The study reported that nearly half (47.9%), weighted to represent national estimates, of the HIV-infected adult population had screening of at least one of the predefined psychiatric disorder in the past 12 months. And, nearly 40% of them were screened positive for drug use within the past 12 months. The prevalence of major depression among the HIV-infected adults was found to be 5 times (36.0% versus 7.6%) to the findings of the National Household Survey on Drug Abuse (NHSDA), which surveyed the presence of major depression, generalized anxiety disorder and panic attacks among the general population in 1994. The prevalence of generalized anxiety disorder among the HIV-infected adults was found to be nearly 8 times higher (15.6% versus 2.1%) and the panic disorders were found to be 4 times higher (10.5% versus 2.5%) than the general adult population in the United States. The NGSDA survey interviewed 22,181 adults and used the screening technique similar to the one used by Bing et al. (2001).

A longitudinal follow up study of the psychological well-being of the children, aged 6-11 years, of mothers having HIV was done by Murphy et al. (2006).[11] HIV-infected mothers were recruited from 14 sites in Los Angeles County, between 1997 and 1999. The investigators in this study followed the children for approximately 6 years and reported the relationship between the mental health of the children and the mother's physical illness over time. Presence of depression, anxiety and aggression were the variable measured to ascertain the mental health status of the child while viral load, CD4+ T cell count and Short Form 36 (SF-36) score on physical functioning were taken as measures for mother's physical illness. The study found a strong association between the children's depression, anxiety and aggressiveness, and the lower levels of physical functioning of the mothers. However, this association weakened over time and this decline was higher in mothers who had a better health status at the base line (time of entry in to the study) in comparison to children whose mothers who entered the study with a poor health. This study highlighted the coping skills among children to adjust to the situation they live in. Stability of the disease progression and length of time a person is with the disease are crucial factors in determining the impact of the parent's illness on the child's health.

A high proportion of HIV-infected population has been a past or a current victim of drug abuse. Bing et al. (2001) estimated that 40% of national HIV population in United States had been a drug user in the past 12 months.[86] With such a high population of injection drug users (IDU) among this population it is very likely that a HIV positive parent having children may also be a IDU victim, and this can have more detrimental effects in the child's physical and mental development. The current literature cites numerous studies that looked in to the impact of the HIV infection of parents on the mental health of the child among IDU population. One such study was conducted by Pilowsky et al. (2001).[87] They recruited IDU individuals from 1997 to 1998 and categorized them as HIV seropositive or HIV seronegative based on their medical records. Parental health status was measured by two variables: presence of a medical condition (diabetes, cirrhosis, hepatitis, sepsis, pneumonia, pulmonary tuberculosis, cancer, and endocarditis), and reported difficulty in performing activities of daily living (housework/housecleaning, shopping for food, cooking/preparing food, doing laundry and using public transport). The child's mental health status was measured using the Child Behavior Check List (CBCL) that provides a score on the child's emotional and behavioral status.[69] The CBCL also provides separate score for the internalizing as well as externalizing behavioral symptoms. Internalizing behaviors include symptoms such as anxiety and depression while externalizing behaviors include attention-deficit hyperactivity, aggressive conduct, defiant and disruptive behaviors, etc. Such behaviors can have serious long term consequences such as academic failure, severe psychiatric disorder, and criminal involvement.[88] This study did not find any significant relationship between the HIV status of the IDU parent with the internalizing (OR: 1.10; 95% CI: 0.37-3.27) and externalizing (OR: 1.17; 95% CI: 0.43-3.14) behaviors of the children. One of the reasons provided by the investigators for this finding was the possibility that the parents may not have disclosed their HIV status to their children. But the parent's medical illness (OR: 4.67; 95% CI: 1.21-18.05) and presence of depression (OR: 4.58;

95% CI: 1.45-14.50) were found to be significantly associated with internalizing behavior symptoms only.

In another study Pilowsky et al. (2003) repeated the study among the same population, which was the intravenous drug users and took the parental disclosure of their HIV status to their children in to consideration.[89] The study found that children of HIV-infected parent were almost 8 times as likely (OR: 7.80; 95% CI: 1.56-39.09) to have a disruptive behavior disorder compared to children of HIV negative parent among those parents who had disclosed their HIV status to their children. It also reported that parental depression was associated with more than 3 fold increase in the prevalence of disruptive behavior disorder among their children (OR: 3.49; 95% CI: 1.11-11.04).

CHAPTER 3: METHODOLOGY

This chapter provides a detailed description of the concepts used to design, operationalize and analyze the study hypotheses. The chapter also explores the various other concepts and models present in the current literature that has been used to build the conceptual framework for this study.

3.1 Designing of Conceptual Framework

The conceptual model for this study is based upon two pivotal models found in the healthcare study literature - The Andersen's healthcare utilization behavioral model[30] and Grossman's human capital and demand for health model.[31]

With the understanding of the concepts illustrated in Chapter 1 a proposed model for the child's health outcomes was derived. The fundamental basis of the model was that the child's health outcome is a function of the parent's health investment in them and that the degree of health investment was a function of the parent's health status. Further, the health investments are determined by the child's predisposing factors, need factors (parent's health status), and enabling factors. The health status of the parent was also a function of their predisposing factors, enabling factors, need factors and other health related inputs. Predisposing factors such as race and ethnicity of the child was considered to be same as that of the parent and represented the parent's genetic contribution to an extent. The age and education level of the child were included as predisposing factors in to the model. The presence of a physical or a behavior related disease in the child formed the child's need factors.

Child's enabling factors incorporated their regular source of care, access to health insurance, access to prescription and dental insurance and access to adequate means of transportation. Since children have limited or no source of income hence parent's income replaced the child's income variable. Age and level of education of the parent were included in the model as efficiency parameters. Since this model considers family as the unit of operation marital status of the parent and number of siblings in the family was also included in the model. For the purpose of this study a modified version of the Parent-Child Healthcare Behavior Model discussed in Chapter 1 was used.

This version was named as Modified Parent-Child Healthcare Behavior Model and has been illustrated in Figure 3-1. The child's health outcome parameters considered for the purpose of this study were body mass index, physical and mental health status and performance of the child in the school which was measured as number of school/daycare days missed due to illness.

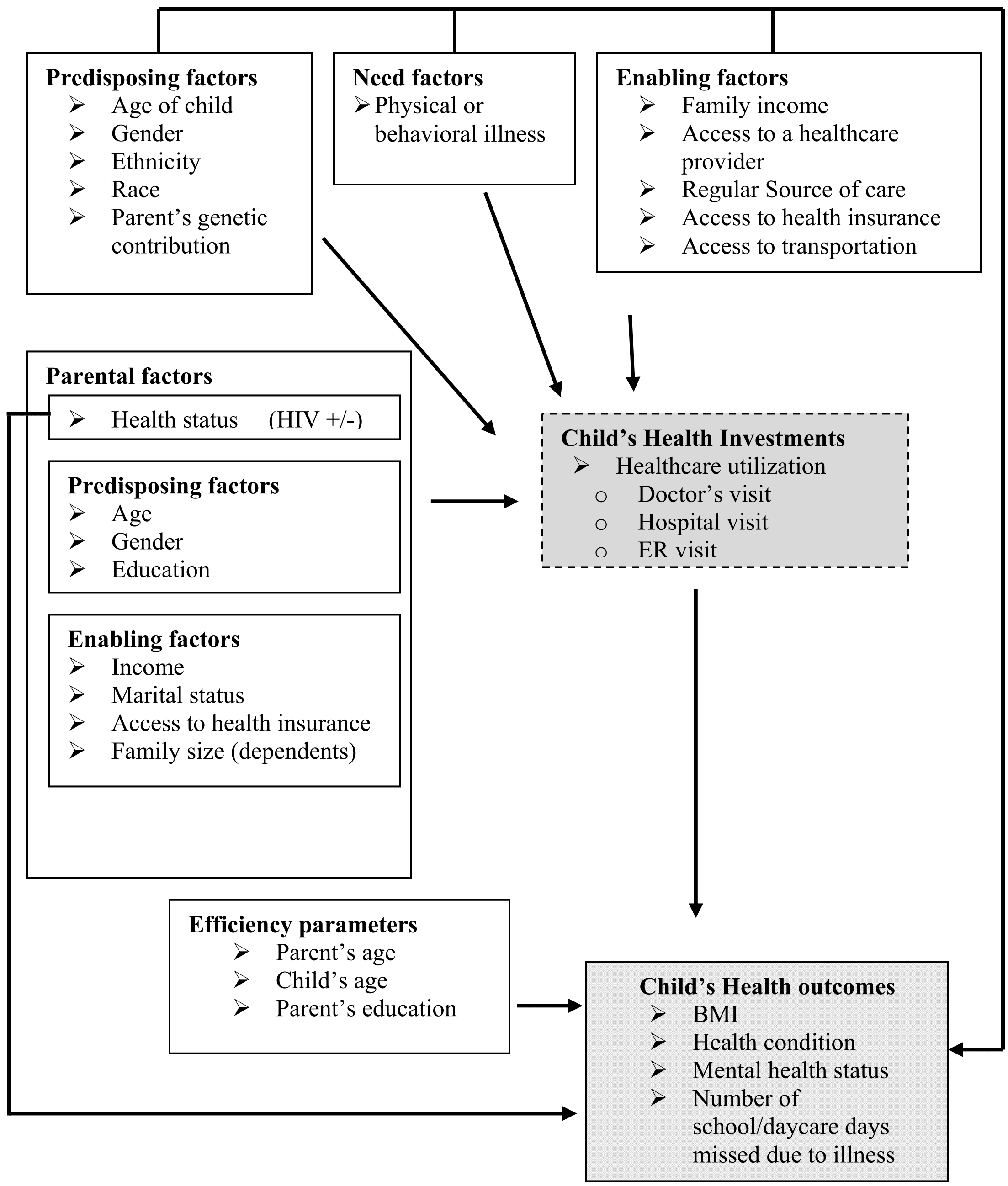


Figure 3-1: Modified Parent-Child Healthcare Behavior Model

Adapted with permission from Andersen Healthcare Utilization Behavioral Model (Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* 1995;36:1-10)[30] and Grossman Human Capital Model (Grossman M. The demand for health: a theoritical and emperical investigation. *NBER Occasional Paper 119, New York.* 1972.)[31]

3.2 Research Design

3.2.1 Study Design

This study is a cross-sectional comparative analysis of the variables of interest between HIV seronegative children living with their HIV seropositive parent(s) and HIV seronegative parents.

3.2.2 Study Population

The population for this study was the uninfected children living with their HIV seropositive parents. However, in order to make a reasonable interpretation of the results a benchmark or a comparable population was eminent. In this study, the uninfected children living with HIV seronegative population in the US was taken as the comparative group. For the purpose of clarity all uninfected children of HIV seropositive parents will be referred as the 'primary group', where as uninfected children of HIV seronegative parents will be referred to as 'comparative group.'

The information regarding the uninfected children of HIV-infected parents was collected through a primary data collection conducted at the study settings. Due to limited resources available for the study the information on the uninfected children of HIV uninfected parents were taken from the 2006 Medical Expenditure Panel Survey (MEPS) database. MEPS is a nationally represented healthcare utilization survey of the non-institutionalized US population. The Agency of Healthcare Research and Quality (AHRQ), an agency within US Department of Health and Human Services (HHS), has been conducting this survey since 1996. MEPS database consists of annual estimates of the national health expenditures, healthcare utilization and access, and health insurance information for non-institutionalized US population.[90]

3.2.2.1 Inclusion Criteria

HIV seronegative children aged between 2 yrs and 15 yrs of HIV seropositive as well as HIV seronegative parent(s) were included in this study. A parent was identified as HIV seropositive if they had a prior diagnosis of HIV/AIDS (ICD-9-CM 042, 043, V08) by a physician and has at least one record of a HIV positive serological test result in the past 6 months in their medical records. A parent was defined HIV seronegative if there were no diagnosis of HIV/AIDS (ICD-9-CM 042, 043, V08) in their medical records at the point of entry into the study. Only those parents who provided their informed consent to voluntarily participate in the study were included. Since the comparative group (children of HIV seronegative parents) was identified from the MEPS data the inclusion criteria to obtain an informed consent was not applicable.

3.2.2.2 *Exclusion Criteria*

Children born before the detection of the HIV status of the parent were excluded from the study. Parents who refused or for any reason did not want to continue with the interview process were excluded from the study. All respondents of incomplete questionnaires were excluded from the study. Children of HIV seropositive parents currently not residing with their infected parent were excluded from the study. Also if the respondent was already interviewed in any of the other sites designated as study settings in this study were excluded to avoid duplication.

3.2.3 Study Setting

For this study three locations were identified as study sites to recruit potential participants. And these were - The Adult Special Care clinic, Friends for Life and Hope House Daycare.

3.2.3.1 *The Adult Special Care Clinic*

The Regional Medical Center, Memphis, has a dedicated outpatient clinic for HIV/AIDS-infected patients. This clinic is called the 'Adult Special Care Clinic' and it provides treatment to almost 2000 patients a year. The site being a government-run health center is a point of care for majority of the HIV-infected population in Memphis.

3.2.3.2 *Friends for Life*

Friends for life specifically provide psychological counseling, basic needs, and critical services to HIV-infected individuals, and also coordinate outreach programs in order to improve the mortality and morbidity associated with the infected. They organize free food distribution activities on selected days of the week, conduct health related seminars and regular self-motivational activities, and even conduct free HIV screening tests. They have more than 500 patients enrolled as members who regularly attend the activities organized by the organization. (www.friendsforlifecorp.org)

3.2.3.3 *Hope House Daycare*

Hope House is the only agency in the state of Tennessee that provides a day care for children and social service to families affected by HIV. Though HIV-infected children were not the study population for this research parents of these children were potential respondents. (www.hopedaycare.org)

The investigator had a few initial meetings with the management of these organizations and discussed the feasibility of approaching the study population and the approval procedure required by the respective organizations to access this group. For all these organizations the approval from the institutional review board (IRB) was the main document required along with a copy of the research proposal explaining the purpose, methodology and study instruments to be used.

3.2.4 Study Sample

Sample size estimation using statistical methods require the standard deviation, type I and type II error estimates, and the effect size of the study population. The level of significance (type 1 error) for this study was at 0.05 level and a power of 0.80 (type II error) were defined in order to test the hypothesis. The standard deviation and the effect size was calculated from a small pilot study that was conducted by the investigator using the MEPS 2001-2006 database on the difference in the healthcare utilization among uninfected children of HIV seropositive and seronegative parents.[91] The required sample size for a one-tail hypothesis was then calculated using the following formulae:

$$N > 2\{(z_{2\alpha} + z_{2\beta})\sigma / \delta_1\}^2$$

where, N = sample size
$z_{2\alpha} = 1.64$
$z_{2\beta} = 0.842$
σ = standard deviation
δ_1 = effect size (absolute difference between means)

The main variables of interest in the study were number of physician visits, hospital visits, emergency room visits and number of days missed school/daycare due to illness. Following minimum sample size requirement for the various variables were estimated (Table 3-1).

Among the various sample size estimates the largest sample size was found to be ≈70 in a group, hence this number was taken as the minimum sample size of participants in each of the groups in order to have the required statistical power for the tests.

Table 3-1: Estimating the sample size for the study

Variable	SD (σ)	Mean 1	Mean 2	Effect size (δ1)	N pairs
ER visits	0.420	0.22	0.083	0.137	57.90
Physician visits	5.700	3.440	1.2	2.24	39.89
Inpatient visits	0.460	0.07	0.24	0.17	45.10
Zero nights hospital stays	3.290	2.29	3.5	1.21	45.54
Number of days missed school	0.010	0.003	0	0.003	68.45

3.2.5 Operationalization of Determinants

3.2.5.1 Child's Predisposing Factors

The predisposing factors of the children include their age, gender, race and ethnicity.[32] Since most of the health related decisions are taken the parent on behalf of their children hence education level of the child was not considered as an efficiency parameter.[32] By including the factors such as race and ethnicity the effects of parent's genetic contribution was captured to a large extent. Other effects of the parent's genetic constitution have not been considered for the sake of the operationalization and hence were beyond the scope of the study.

- Age: Age was computed from the date of birth information of the child. Number of years completed as of January 1st, 2009, was taken as the age of the child.
- Gender: The variable was categorized into male and female.
- G40
- Race: The race of the study respondents were categorized into White, Black, Asian, Native Hawaiian/Pacific Islander, American Indian/Alaska Native, and Others. Post data collection analysis showed that the study population consisted of only whites and blacks.
- Ethnicity: This variable was categorized as Hispanic and Non-Hispanic. Post data collection showed 98% of the study participants to be Hispanics. Therefore, due to lack of variability of this factor in the study population, the ethnicity variable was dropped from the model.

3.2.5.2 Child's Need Factors

The child's health status was determined from the parent reported child's perceived health status. Each parent was asked the question "My child seems less healthy than other that I know?" The parents had to select one of the five options: 1) Definitely true 2) Mostly true 3) I don't know 4) Mostly false and 5) Definitely false. Options 1 and 2 were considered as worst/bad health and options 4 and 5 were taken as good/excellent health.[92,93]

3.2.5.3 Child's Enabling Factors

Access to healthcare resources enables the child to avail and utilize inputs which are crucial in the production of 'good health'. Variables considered as enabling factors in this study included access to health insurance, access to prescription and dental insurance, having a regular source of care and access to transportation. Income is a key variable, however most children have no defined annual income. Since the parents have the responsibility to cater to the financial requirements of the child, income of the parents was considered in place of income of the child.

- Access to health insurance: In the current healthcare system in the United States the health insurance status of an individual is a prime factor that governs access to the healthcare resources. A child was categorized as 'insured' if the child had health insurance, else marked as 'uninsured'. Insured children were further categorized as 'public' and 'private' based on the source of funding for the insurance program they were enrolled in. For statistical reasons, i.e. low cell counts, categories 'public' and 'private' were combined together. Therefore in the regression analysis the groups were dichotomized as 'insured' and 'uninsured'.
- Regular source of care: The parents were asked whether there was a particular doctor's office, clinic, health center, or other place that their child usually goes if he/she was sick or if the parent required any advice regarding their child's health. If the child had a particular provider/clinic/health center then the regular source of care was marked as 'present', else marked 'absent'.
- Access to healthcare provider: Parents were asked to rate their child's access to get to their healthcare provider from the following options: very difficult, somewhat difficult, not too difficult and not at all difficult. For the purpose of analysis and interpretation categories 'very difficult' and 'somewhat difficult' were combined in to a single variable as 'very/somewhat difficult'.
- Access to transportation: This was measured using two variables:
  - Mode of transportation: Parents were asked about the mode of transportation generally required to get to their healthcare provider. This variable was categorized as drives, is driven, uses a taxi, public transport, or has to walk.
  - Transportation time: The parents were asked to approximately estimate the time taken by the child, taking in to consideration the mode of transportation used, to get to the healthcare provider. The time span was categorized as less than 15 minutes, 15-30 minutes, 31-60 minutes, 61-90 minutes, 91-120 minutes, and more than 120 minutes (2 hours). For statistical reasons, i.e. zero cell counts, last four categories were combined to for a common category of 'More than 30 minutes'.

3.2.5.4 Parental Factors

Parent's age, gender, level of education, marital status, family size, and parent's perception of their child's health were included as the parental factors in this study.

- Age: Age was computed from the date of birth of the parent. Number of years completed as of January 1st, 2009, was taken as the age of the parent.
- Gender: The variable was categorized into male and female.
- Level of education: This variable was calculated in two ways. One was the number of years of education completed by the parent. And second variable was based on the highest degree attained by the parent and this was categorized as no degree, GED, high school diploma, bachelor's degree, master's degree, or any other. In the analysis number of years of education was taken as the variable for

age of the parent and it was dichotomized as ‘less than 12 years’ and ’12 years or more’.

- Marital status: The parent was asked to select one of options that best described their marital status – single, married or divorced. Widowed and divorced parent were categorized as ‘single’ for the purpose of analysis in this study.
- Income: The cumulative income of the family provided by the parent was taken as the measure of the family income in this study. For analysis purpose, it was categorized in to ‘less than $10,000’ per year, ‘$10,000 - $20,000’ per year and ‘above $20,000’ per year.
- Access to health insurance: Parents were categorized as ‘insured’ if they had any health insurance, else marked as ‘uninsured’. Insured parents were further categorized as ‘public’ and ‘private’ based on the source of funding for the insurance program they were enrolled in. For statistical reasons, i.e. low cell counts, categories ‘public’ and ‘private’ were combined together. Therefore in the analysis the groups were dichotomized as ‘insured’ and ‘uninsured’.
- Access to prescription drug insurance: If the health insurance had a prescription coverage as a part of the insurance policy then the parent was marked ‘yes’, else marked as ‘no’.
- Family size is represented by the number of dependents in the family. Number of dependents was defined as number of children less than 18yrs living in household plus the spouse (if any).
- Perception of child’s health: MEPS documents the use of 5 questions from the General Health Subscale of the Child Health Questionnaire (CHQ) that captures the parent’s perception of their child’s health.[94] Parents were asked to rate the questions on a 5 point scale ranging from “Definitely True” (1), “Mostly True” (2), ”I don’t know” (3), “Mostly False” (4) to “Definitely False” (5).

3.2.5.5 Health Status of the Parent

Health status of the parent is the key determinant of the healthcare investments and health outcomes of a child. The health status of parent in this study is defined in terms of their HIV/AIDS status (positive or negative). In case of HIV seropositive parents, severity of HIV infection was identified as an important variable that would dictate the physical functionality of the parent.

One of the pivotal markers for the severity of HIV infection is the CD4 count of the person. Human immune system has numerous types of cells that fight diseases. CD4 lymphocyte T cells are one such disease fighting cells in the body. HIV virus attacks these cells and thereby affects the body’s immune system, thus making the infected person prone to other disease attacks and illnesses. In a non-HIV-infected person the CD4 count ranges from 700 – 1000 in a single drop of blood. A HIV-infected person is said to be normal if the CD4 count is above 500 and as it drops below 200 the person is classified as HIV/AIDS patient. The transition from HIV to AIDS may take few months to several years depending upon the person’s previous health and immune system. Hence

CD4 count and the number of years since HIV-infected is a good measure of the HIV patient's severity of disease and also their health status.

3.2.5.6 Healthcare Utilization

- Number of times the child has made a visit to a doctor for any medical reason in the past 12 months. A dichotomous variable was created if the child had a doctor visit in the past 12 months for any medical reason.
- Number of times the child has made a visit to a hospital for any medical reason in the past 12 months. A dichotomous variable was created if the child had a hospital visit in the past 12 months for any medical reason.
- Number of times the child has made a visit to an emergency room for any medical reason in the past 12 months. A dichotomous variable was created if the child had an emergency room visit in the past 12 months for any medical reason.

3.2.5.7 Health Outcomes

Number of days of school/daycare missed due to sickness and the Body Mass Index (BMI) of the child were taken as the measure of the child's health outcomes.

- Number of school/daycare days missed due to illness was taken as one of the measures for the health outcomes of the child. The justification is that children with lower health status will have higher number of school days or daycare days missed because of sickness compared to healthier children. The variable was dichotomized as 'have missed' and 'have not missed' a school/daycare day due to illness in the past 12 months.
- Body Mass Index: BMI has been a measure of child's growth for various clinical purposes. The BMI standards based on height/weight and age developed by the World Health Organization (WHO) depicts the child's normal growth among children irrespective of ethnicity, socio-economics status as type of feeding.[95] The BMI is calculated by dividing weight in pounds (lbs) by height in inches (in) squared and multiplying by a conversion factor of 703.[96]

$$\text{BMI} = \text{weight (lb)} / [\text{height (in)}]^2 \times 703$$

Interpreting BMI among children has been debated and lacks consensus.[97] However, researchers have used various methods to interpret the BMI figures in the pediatric population.[98] The International Obesity Task Force suggests the percentile system in which the children over the 80^{th} percentile are overweight, as this corresponds to a body mass index of 25 in men as well as in women at the age of 18 yrs.[99,100] The Center for Disease Control and Prevention (CDC) recommends above 85^{th} percentile as a cut-off point for a child to be categorized as 'overweight'.[101] In this study, children with BMI above the 85^{th} percentile were grouped as 'overweight', those below the 5^{th} percentile were grouped as 'underweight' and those children with BMI falling in between the 5th and the 85th percentile were grouped as 'normal'. For the purpose of analysis, the variable was dichotomized in to 'normal weight' and 'not normal (under/over) weight'.

After BMI is calculated for children and teens, the BMI number was plotted on the CDC BMI-for-age growth charts (for either girls or boys) to obtain a percentile ranking. Percentiles are the most commonly used indicator to assess the size and growth patterns of individual children in the United States. The percentile indicates the relative position of the child's BMI number among children of the same sex and age. The growth charts show the weight status categories used with children and teens (underweight, healthy weight, overweight, and obese). The BMI charts for boys (2-20yrs) please refer to Appendix B.1 and for the BMI charts for girls (2-20yrs) please refer to Appendix B.2.

- Prescription drug status: This includes the child's physical or behavioral conditions. Presence of a medical or a mental health need was determined from the medications the child has been currently prescribed. Parents were asked, whether the child was on any kind of prescription medications currently, apart from vitamins, and if yes, then whether the medication was for a medical/physical, behavioral or any other reason. Literature provides enough evidences which speaks about significant correlation between perceived health status and the occurrence of chronic illnesses and physician's ratings of health status in cross-sectional observational studies.[92,93,102,103]

3.2.6 Study Instrument

Information was collected from parents using structured questionnaires with proven validity and reliability scores. For measuring the access, utilization and health outcomes standardized questionnaires are available in the current literature. The questionnaires used in this study were taken from the standardized questionnaires used by Agency for Healthcare Research and Quality (AHRQ) for collecting Medical Expenditure Panel Survey (MEPS) data. MEPS is a nationally represented sample population on US healthcare utilization and medical expenses, and are reliable as well as validated.[104] Two different questionnaires were developed in order to get the information on both parents as well as the children.

3.2.6.1 Questionnaire for Parental Factors

The first questionnaire collected the socio-demographic, health insurance related and health related information of the HIV-infected parent (Appendix B.3).

3.2.6.2 Questionnaire for Child Factors

The second questionnaire was designed to collect data on the variables of interest (health investments, access, healthcare utilization, and health outcomes) of the children (Appendix B.4). All the information regarding the child was obtained from the parent (parent reported information).

3.2.7 Study Data Collection Plan

Though the study aimed to find the health and healthcare related information of children, all the information required to test the hypothesis was taken from the HIV seropositive parent (parent reported information). Such a design protected the privacy of the patient population who may not appreciate any attempt from the investigator to directly question their children. Also studies suggest that less than half of the parents actually inform their children about their HIV status.[48] Hence, it was necessary to avoid any direct interaction with the HIV-affected children. Such an attempt may hinder free participation of the patient population in the study and may negatively impact the sample size. MEPS also followed similar data collection procedure for their Child Health and Preventive Care section. Questions were asked about each child (under the age of 18 excluding deceased children) to the applicable respondent.

In the study a convenient sampling technique was used to collect information of uninfected children living with HIV seropositive parent. In the primary data collection the initial recruitment of the participants were done by the case managers (in Adult Special Care Clinic) or by the social workers (in Friends for Life and in Hope House Daycare). The HIV seropositive parents had their walk-in as well as scheduled visits to the Adult Special Care Clinic and at the Friends for Life study sites. During their visit the case managers/social workers approached each visitor to identify parents who have children (aged 2-15 yrs) and were currently living with them. Once identified, they were then directed to the principal investigator for a detailed explanation of the study objective and agreed participants were interviewed upon informed consent. At the Hope House Daycare, recruiting was done at the front office when each parent came in to pick their children back home. As the Friends for Life and Hope House had a social orientation hence the investigator was advised by the social workers to wear a casual dress. However, the Adult Special Care Clinic has a profession/clinical orientation; hence the investigator was advised by the case managers to wear a formal dress along with a white coat that displayed the name (Arijit Ganguli) and designation (Graduate PhD Student).

All HIV/AIDS seropositive patients having a child (2-15yrs) living with them were approached as per the pre-designed script (Appendix C.3). The study objectives and the procedure were explained to each and every participant before asking them the study questions. The answering of the questions by a parent was considered as their permission (informed consent) to use their responses to the survey questions in the study. During the survey the study participants were asked to provide information related to their child's healthcare utilization, access to healthcare services and their health outcomes. The study participants (HIV seropositive parent) were asked questions (refer to Questionnaire Parent) regarding their demographic information (age, gender, race, and ethnicity), socio-economic status (level of education and family income), and certain basic questions on their current health status (length of HIV seropositive status and CD4 counts, as a measure of their severity of disease). Then each participant was asked questions regarding the healthcare access, insurance status, healthcare utilization, and health outcomes of their child/children (refer to Questionnaire Child). In case of more than one child, parents were required to fill separate questionnaires for each child.

No monetary or non-monetary benefits of any kind were provided to the study participants to enroll in the study. To maintain anonymity all the study participants, data was encrypted and each participant was given a 'participant identification number' as a form of identity. No information regarding the name, address or any other form of contact information of the study respondents or their children was collected. Since this was a cross sectional study hence such a study plan ensured that no reported information could be traced back to the actual respondent for any follow up information.

The information of the comparative group (uninfected children of HIV seronegative parent) was taken from the Medical Expenditure Panel Survey (MEPS) 2006 database, a nationally representative survey conducted by AHRQ.

3.2.8 Required Approvals and Documentations

All necessary documentation was done to obtain complete authorization from the University of Tennessee Institutional Review Board (UT-IRB), and the management of Adult Specialty Clinic, Friends for life and Hope House to conduct the study (Appendix C). This study was exempted from continuing oversight from the UT- IRB because the data collected from the survey cannot be linked back to any particular study subjects. No information identifying the study participants (HIB seropositive parents) name, address or contact details will be taken. This study was a cross sectional study and no follow up of the study participants was required. And it would be impossible to contact the subjects selected from the MEPS database in order to get their informed consent. Additionally, a waiver of the requirement of assigned consent form was obtained and the willingness of the respondent to answer the survey questions was taken as the informed consent of the respondent.

Since the study deals with socially marginalized population all the data collected were encrypted and stored in a password protected computer. No data was sent or received through emails. All completed questionnaires were kept in a lock and key cabinet. Only the principal investigator had the authorization to access these data.

3.2.9 Study Analysis

As the data on both the groups (study and comparative group) was taken from two different sources, the possibility of the observed as well as unobserved variables being similar was questionable. Hence, to minimize the bias during interpretation both the groups were matched based on their propensity scores or likelihood to be in a particular group.

3.2.9.1 Propensity Score Based Matching

This research is an observational study comparing various variables of interest between two groups. One of the major limitations of an observational study design is the lack of randomization in the assigning of individuals to either the group of interest (treatment) or the comparative group (control). Randomization ensures that each individual in a study has equal probability of being in a particular group (treatment versus control) therefore reduces the differences in the measured an unmeasured variables. Such a design guarantees that only one difference exists in assigned group status, and this difference is the likely cause for any observed difference in the outcomes.[105] In the absence of randomization, the differences in the observed and unobserved covariates between the groups induce bias in the estimation of the variables. As a solution to minimize the confounding effects of these covariates propensity score matching technique is advised.[106] Some other techniques available in the literature and used frequently in observational studies are stratification and regression adjustments based on various covariates.

Propensity score is defined as the “conditional probability” of an individual being in a particular group (treatment / control). Rosenbaum and Rubin proposed the matching based on propensity scores in observation studies reduces this bias.[107] The logical justification behind this concept is that individuals with equal propensity scores have equal probability of being assigned to either the treatment or the control group, very similar to a randomized study design. In this technique every individual in the treatment group is matched with an individual in the control group based in their propensity scores. Propensity score techniques use a logistic regression method to predict the probability of being assigned to a group (treatment versus control) based on a set of predictors such as pretreatment demographic, socioeconomic and clinical characteristics. The matching of the propensity scores, as outlined by Rosenbaum and Rubin, can be done in three ways: (1) nearest available matching on the estimated propensity scores; (2) Mahalanobis metric matching including the propensity scores; and (3) nearest available Mahalanobis metric matching within calipers defined by the propensity scores.[108] All the three techniques have been used extensively in the statistical as well as medical literatures. However, the third technique produces the best balance for the covariates between the two groups.[106] This study uses the third technique to match the individuals hence will only be discussed. Mahalanobis Distance[109] (MD) is an estimate of the distance between two dimensional points measured by the statistical variations in each component of the point.[110] The Mahalanobis distance is calculated using the following expression,

$$D(X,Y) = (X-Y)^t C^{-1}(X-Y)$$

where, X and Y are two points obtained from similar distribution with covariance matrix C and D(X,Y) denoting the Mahalanobis distance between points X and Y.[111]

3.2.9.2 Method for Matching

Based on the demographic factors (age, gender, race and ethnicity), socioeconomic factors (family income, parent's level of education, parent's marital status, number of dependents and the geographical region) and parent's insurance status, a propensity score and the Mahalanobis distance of all study participants were calculated. Then the children who were living with their HIV seropositive parent(s) were randomly ordered, and the first child was selected. Based on the propensity of this child (living with HIV seropositive parent), all children from the comparative group (children living with HIV seronegative parents) with a propensity score with in a caliper of ±0.001 were selected and grouped as potential matched individuals. Then based on the Mahalanobis distances, calculated previously, two children were selected from the potential matched individuals using a caliper of a quarter (0.25) of a standard deviation of the logit of the propensity score.[105] Similarly, each child in the first group (uninfected children of HIV seropositive parents) was matched with two children from the comparative group.

In the absence of specific ZIP codes of the respondents matching was done base on geographical region as defined in MEPS. In MEPS, respondents are categorized in to four major geographical zones – Northeast, Midwest, South and West.[104] Since the primary collection was done in Memphis, Tennessee, the comparative group meeting the inclusion criteria consisted of respondents from the 'south' region only.

The values and states for each region in the MEPS 2006 database include the following:

- *Northeast*: Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont.
- *Midwest*: Indiana, Illinois, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin.
- *South*: Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia
- *West*: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.

3.2.9.3 Analysis for Differences Post-Matching

A chi squared test was conducted to analyze to ascertain that no differences existed between the two groups post-matching in terms of the various demographic, socioeconomic and health status variables. The only difference was the HIV health status of the parent and hence any differences observed during the hypothesis testing can be attributed to the parent's HIV status.

3.2.9.4 Descriptive Statistics

Frequency distribution of the sample population was done to describe the distribution in terms of the demographic, socioeconomic and health factors for the child as well as the parent. All the results of the frequency distributions were reported as numbers and percentages in a tabular form.

3.2.9.5 Inferential Statistics

For the inferential statistics bivariate and multivariate models were used to test the study hypothesis. Depending upon the hypothesis, two different multivariate models were used in alignment went the Parent-Child Healthcare Behavior model (refer to Figure 3-1)

3.2.9.5.1 Model I

In this model the dependent variable was the healthcare utilization variables such as doctor visits, hospital visits and the emergency room visits. According to the Parent-Child Healthcare Behavior Model, the healthcare utilization of an individual is a function of the child's predisposing, need and enabling factors, and the parent's health status, and their predisposing and enabling factors.

Y(Utilization) = f(parent HIV status, child's predisposing, need & enabling factors, parent's predisposing and enabling factors)

3.2.9.5.2 Model II

In Model II, the dependent variable was the health outcome variables. In accordance with the conceptual framework of this study the health outcomes of the child was the function of the child's predisposing, need and enabling factors, efficiency parameters, healthcare utilization variables of the child and the health status of the parent. The conceptual framework showed that the health of the parent impacts health outcomes in two different ways. According to Grossman's Human Capital Model, every child is born with an initial stock of health and this initial stock is highly driven by the health stock of the parent. Therefore, parent's health influences the child's health and hence the health outcomes directly. Subsequently, parents also make healthcare decisions on behalf of the child and decide the quality and quantity of the healthcare resources used by the child. Thereby controlling the use of healthcare resources the parent indirectly influence the child's health outcomes, as both Andersen as well as Grossman model signifies the importance of use of healthcare resources as predictors/inputs of health outcomes. In order to incorporate the healthcare utilization variable as a function of the parent and child's predisposing, need and enabling factors, the predicted value of the utilization variables were used in place of the observed values in this model. The predicted values were calculated using the Model I.

Y(Health Outcomes) = f(parent HIV status, child's predisposing, need & enabling factors, efficiency parameters, predicted value of utilization)

3.2.9.5.3 Hypothesis Testing Using Bivariate Analysis

For categorical variables a chi-square (χ^2) analysis was preformed and for continuous variables the difference between the means among the groups were performed using the student 't' test statistical method. For all statistical inferences the level of significance was at 0.05. The null hypothesis for these tests was:

H_0: *No differences exist between the groups*
H_A: *Differences exist between the groups*

3.2.9.5.4 Hypothesis Testing Using Multivariate Logistic Regression Model

A logistic regression was performed on binary dependent variables with the HIV status of the parent (HIV seropositive versus HIV seronegative parent) as the independent variable adjusting for factors in accordance with Model I or II.

$$Y(Utilization) = b_0 + b_1\text{ 'HIV parent'} + b_2\text{ 'child's age'} + b_3\text{ 'child's gender'} + b_4\text{ 'race'} + b_5\text{ 'income'} + b_6\text{ 'child's insurance'} + b_7\text{ parent's age'} + b_8\text{ 'parent's gender'} + b_9\text{ parent's marital'} + b_{10}\text{ 'parent's education'} + b_{11}\text{ 'parent's insurance'} + b_{12}\text{ 'dependents'} + b_{13}\text{ 'child's health'} + b_{14}\text{ 'access'} + b_{15}\text{ 'source'} + \varepsilon$$

$$Y(Outcomes) = b_0 + b_1\text{ 'HIV parent'} + b_2\text{ 'child's age'} + b_3\text{ 'child's gender'} + b_4\text{ 'race'} + b_5\text{ 'income'} + b_6\text{ 'child's insurance'} + b_7\text{ parent's age'} + b_8\text{ 'parent's education'} + b_9\text{ 'child's health'} + b_{10}\text{ 'access'} + b_{11}\text{ 'source'} + b_{12}\text{ 'predicted doctor visit} + b_{13}\text{ 'predicted hospital visits} + b_{14}\text{ 'predicted ER visits'} + \varepsilon$$

3.2.9.5.5 Hypothesis Testing Using Multivariate Negative Binomial Regression Model

In order to quantify the differences in the utilization of healthcare resources by the children living with seropositive and seronegative parent(s), a negative binomial regression model was used. Negative binomial is a general distribution often used as an alternative to the Poisson distribution. This approach ensures inclusion of a random component that takes in to consideration the uncertainty about the actual rates at which events occurs for individual cases.[112] Negative binomial accommodates the phenomenon of over dispersion which is generally found to count data when assumption of equality of mean and the variance is violated.[113,114] The Poisson model also assumes that all differences among the individuals to use resources were explained by the variables expressed in the model equation. However, in real life cases, such an assumption is violated as several unobserved variations may not be explained by all the variables measured in the study. Negative binomial model address this constrain of the Poisson model.[112] The model fit statistic for negative binomial regression is the dispersion parameter 'α' using a maximum likelihood-ratio test. If the confidence interval window of the dispersion parameter does not include one, then the negative binomial model fits the data. (Note: As the data is log transformed in the SAS analysis, the confidence intervals are actually in the log form and therefore needs to be converted in to its exponential form before interpretation). In case the confidence interval consists $\alpha=1$, then the data fits a Poisson distribution and a Poisson regression model needs to be used for analyzing the quantity differences.[115] Interpretation of the coefficients of the negative binomial regression using the log transformed data was done by taking the natural exponential value [$\exp(\beta_1)$] of the regression coefficients.

A multivariable model was developed to fit the Poisson/Negative Binomial model and is as follows:

Log(Utilization) = b_0 + b_1 *'HIV parent'* + b_2 *'child's age'* + b_3 *'child's gender'* + b_4 *'race'* + b_5 *'income'* + b_6 *'child's insurance'* + b_7 *parent's age'* + b_8 *'parent's gender'* + b_9 *parent's marital'* + b_{10} *'parent's education'* + b_{11} *'parent's insurance'* + b_{12} *'dependents'* + b_{13} *'child's health'* + b_{14} *'access'* + b_{15} *'source'* + ε

Log(Outcomes) = b_0 + b_1 *'HIV parent'* + b_2 *'child's age'* + b_3 *'child's gender'* + b_4 *'race'* + b_5 *'income'* + b_6 *'child's insurance'* + b_7 *parent's age'* + b_8 *'parent's education'* + b_9 *'child's health'* + b_{10} *'access'* + b_{11} *'source'* + b_{12} *'predicted doctor visit* + b_{13} *'predicted hospital visits* + b_{14} *'predicted ER visits'* + ε

Hypothesis 1: A smaller proportion of children living with HIV seropositive parent(s) have a health insurance compared to children living with HIV seronegative parent(s).

> *H_0: Differences does not exist between the two groups.*
> *H_A: Differences exists in the proportion of insured children between the two groups.*

Hypothesis 2: A smaller proportion of children living with HIV seropositive parent(s) have a regular source of care compared to children living with HIV seronegative parent(s).

> *H_0: Differences does not exist between the two groups.*

H_A: Differences exists in the proportion of children with regular source of care between the two groups.

Hypothesis 3: A smaller proportion of children living with HIV seropositive parent(s) have a prescription drug insurance compared to children living with HIV seronegative parent(s).

H_0: Differences does not exist between the two groups.
H_A: Differences exists in the proportion of children with prescription drug insurance between the two groups.

Hypothesis 4: Higher proportion of children living with HIV seropositive parent(s) take more than 30 minutes to get to a healthcare provider compared to children living with HIV seronegative parent(s).

H_0: Differences does not exist between the two groups.
H_A: Differences exists in the proportion of children who take more than 30 minutes to get to a health provider between the two groups.

Hypothesis 5: Higher proportion of children living with HIV seropositive parent(s) indicate having difficulty in getting to a healthcare provider compared to children living with HIV seronegative parent(s).

H_0: Differences does not exist between the two groups.
H_A: Differences exists in the proportion of children indicating difficulty in getting to a healthcare provider between the two groups.

*Hypothesis 6***:** Children of HIV seropositive parent(s) have lower likelihood for a doctor visit compared to children of HIV seronegative parent(s).

$$Y(\text{Doctor's visit}) = b_0 + b_1\,\text{`HIV parent'} + b_2\,\text{`child's age'} + b_3\,\text{`child's gender'} + b_4\,\text{`race'} + b_5\,\text{`income'} + b_6\,\text{`child's insurance'} + b_7\,\text{parent's age'} + b_8\,\text{`parent's gender'} + b_9\,\text{parent's marital'} + b_{10}\,\text{`parent's education'} + b_{11}\,\text{`parent's insurance'} + b_{12}\,\text{`dependents'} + b_{13}\,\text{`child's health'} + b_{14}\,\text{`access'} + b_{15}\,\text{`source'} + \varepsilon$$

$$\text{Log(Number of doctors visit)} = b_0 + b_1\,\text{`HIV parent'} + b_2\,\text{`child's age'} + b_3\,\text{`child's gender'} + b_4\,\text{`race'} + b_5\,\text{`income'} + b_6\,\text{`child's insurance'} + b_7\,\text{parent's age'} + b_8\,\text{`parent's gender'} + b_9\,\text{parent's marital'} + b_{10}\,\text{`parent's education'} + b_{11}\,\text{`parent's insurance'} + b_{12}\,\text{`dependents'} + b_{13}\,\text{`child's health'} + b_{14}\,\text{`access'} + b_{15}\,\text{`source'} + \varepsilon$$

Hypothesis 7: Children of HIV seropositive parent(s) have higher likelihood for a hospital visit compared to children of HIV seronegative parent(s).

$$Y(\text{Hospital visit}) = b_0 + b_1 \text{ 'HIV parent'} + b_2 \text{ 'child's age'} + b_3 \text{ 'child's gender'} + b_4 \text{ 'race'} + b_5 \text{ 'income'} + b_6 \text{ 'child's insurance'} + b_7 \text{ parent's age'} + b_8 \text{ 'parent's gender'} + b_9 \text{ parent's marital'} + b_{10} \text{ 'parent's education'} + b_{11} \text{ 'parent's insurance'} + b_{12} \text{ 'dependents'} + b_{13} \text{ 'child's health'} + b_{14} \text{ 'access'} + b_{15} \text{ 'source'} + \varepsilon$$

$$Log(\text{Number of hospital visit}) = b_0 + b_1 \text{ 'HIV parent'} + b_2 \text{ 'child's age'} + b_3 \text{ 'child's gender'} + b_4 \text{ 'race'} + b_5 \text{ 'income'} + b_6 \text{ 'child's insurance'} + b_7 \text{ parent's age'} + b_8 \text{ 'parent's gender'} + b_9 \text{ parent's marital'} + b_{10} \text{ 'parent's education'} + b_{11} \text{ 'parent's insurance'} + b_{12} \text{ 'dependents'} + b_{13} \text{ 'child's health'} + b_{14} \text{ 'access'} + b_{15} \text{ 'source'} + \varepsilon$$

Hypothesis 8: Children of HIV seropositive parent(s) have higher likelihood for an emergency room visit compared to children of HIV seronegative parent(s).

$$Y(\text{ER visit}) = b_0 + b_1 \text{ 'HIV parent'} + b_2 \text{ 'child's age'} + b_3 \text{ 'child's gender'} + b_4 \text{ 'race'} + b_5 \text{ 'income'} + b_6 \text{ 'child's insurance'} + b_7 \text{ parent's age'} + b_8 \text{ 'parent's gender'} + b_9 \text{ parent's marital'} + b_{10} \text{ 'parent's education'} + b_{11} \text{ 'parent's insurance'} + b_{12} \text{ 'dependents'} + b_{13} \text{ 'child's health'} + b_{14} \text{ 'access'} + b_{15} \text{ 'source'} + \varepsilon$$

$$Log(\text{Number of ER visit}) = b_0 + b_1 \text{ 'HIV parent'} + b_2 \text{ 'child's age'} + b_3 \text{ 'child's gender'} + b_4 \text{ 'race'} + b_5 \text{ 'income'} + b_6 \text{ 'child's insurance'} + b_7 \text{ parent's age'} + b_8 \text{ 'parent's gender'} + b_9 \text{ parent's marital'} + b_{10} \text{ 'parent's education'} + b_{11} \text{ 'parent's insurance'} + b_{12} \text{ 'dependents'} + b_{13} \text{ 'child's health'} + b_{14} \text{ 'access'} + b_{15} \text{ 'source'} + \varepsilon$$

Hypothesis 9: Children of HIV seropositive parent(s) have higher likelihood for a missed school/daycare day due to ill health compared to children of HIV seronegative parent(s).

$$Y(\text{School days missed}) = b_0 + b_1 \text{ 'HIV parent'} + b_2 \text{ 'child's age'} + b_3 \text{ 'child's gender'} + b_4 \text{ 'race'} + b_5 \text{ 'income'} + b_6 \text{ 'child's insurance'} + b_7 \text{ parent's age'} + b_8 \text{ 'parent's education'} + b_9 \text{ 'child's health'} + b_{10} \text{ 'access'} + b_{11} \text{ 'source'} + b_{12} \text{ 'predicted doctor visit} + b_{13} \text{ 'predicted hospital visits} + b_{14} \text{ 'predicted ER visits'} + \varepsilon$$

$$Log(\text{Number of school days missed}) = b_0 + b_1 \text{ 'HIV parent'} + b_2 \text{ 'child's age'} + b_3 \text{ 'child's gender'} + b_4 \text{ 'race'} + b_5 \text{ 'income'} + b_6 \text{ 'child's insurance'} + b_7 \text{ parent's age'} + b_8 \text{ 'parent's education'} + b_9 \text{ 'child's health'} + b_{10} \text{ 'access'} + b_{11} \text{ 'source'} + b_{12} \text{ 'predicted doctor visit} + b_{13} \text{ 'predicted hospital visits} + b_{14} \text{ 'predicted ER visits'} + \varepsilon$$

Hypothesis 10: Children of seropositive parent(s) have a higher likelihood to be overweight compared to children of HIV seronegative parent(s).

Y(BMI overweight) = b_0 + b_1 *'HIV parent'* + b_2 *'child's age'* + b_3 *'child's gender'* + b_4 *'race'* + b_5 *'income'* + b_6 *'child's insurance'* + b_7 *parent's age'* + b_8 *'parent's education'* + b_9 *'child's health'* + b_{10} *'access'* + b_{11} *'source'* + b_{12} *'predicted doctor visit* + b_{13} *'predicted hospital visits* + b_{14} *'predicted ER visits'* + ε

Hypothesis 11: Children of seropositive parent(s) have a higher likelihood of being currently on a prescription medication for any health condition compared to children of HIV seronegative parent(s).

Y(Rx medication) = b_0 + b_1 *'HIV parent'* + b_2 *'child's age'* + b_3 *'child's gender'* + b_4 *'race'* + b_5 *'income'* + b_6 *'child's insurance'* + b_7 *parent's age'* + b_8 *'parent's education'* + b_9 *'child's health'* + b_{10} *'access'* + b_{11} *'source'* + b_{12} *'predicted doctor visit* + b_{13} *'predicted hospital visits* + b_{14} *'predicted ER visits'* + ε

Hypothesis 12: Children of seropositive parent(s) have a higher likelihood to being currently on a prescription medication for mental health condition compared to children of HIV seronegative parent(s).

Y(Rx mental) = b_0 + b_1 *'HIV parent'* + b_2 *'child's age'* + b_3 *'child's gender'* + b_4 *'race'* + b_5 *'income'* + b_6 *'child's insurance'* + b_7 *parent's age'* + b_8 *'parent's education'* + b_9 *'child's health'* + b_{10} *'access'* + b_{11} *'source'* + b_{12} *'predicted doctor visit* + b_{13} *'predicted hospital visits* + b_{14} *'predicted ER visits'* + ε

3.2.9.6 Sensitivity Analysis

A sensitivity analysis was carried out incorporating the data that was missed out during the propensity matching scores. In the matching process 9 children did not have a matched pair. The purpose of this step was to see whether the exclusion of this data affected the results significantly. A multivariate logistic regression was carried out for the utilization and health outcome variables and the coefficients and p values were compared with that of the regression results of data conducted without these 9 children.

CHAPTER 4: RESULTS

This chapter summarizes the descriptive, bivariate and the multivariate analysis in order to analyze the study hypothesis and illustrate the impact of the HIV status of the parents on the health outcomes, healthcare utilization and access to healthcare resources of their children residing with them. The results have been presented in two different sections: descriptive statistic of the sample population and the inferential statistic for bivariate and multivariate hypothesis testing.

4.1 Descriptive Statistics

4.1.1 Study Sample

The data for the primary group (uninfected children living with their HIV seropositive parents) in this study was collected from three study sites and the comparative group (uninfected children living with HIV seronegative parents) was teased out from the 2006 MEPS data. The data for the primary group was collected between January 2009 and March 2009, and the data represented the healthcare utilization of the respondents for the year 2008.

Figure 4-1 provides a schematic representation of the data mining process to get the study sample. For the primary data collection phase, a total of 92 HIV seropositive parents were recruited by the various case managers and social workers. Out of these, 90 parents agreed to participate in the study and 2 denied participation, thereby giving a response rate of 97.82%. These 90 parents provided information on their HIV seronegative (uninfected) children through a survey questionnaire session. In all, information on 98 uninfected children was obtained who met the inclusion-exclusion criteria of the study.

The MEPS Household component of the Medical Expenditure Panel Survey dataset of 2006 consisted to 34,145 participants, and the MEPS Medical condition file, which is an event level data, had 105,116 records. Out of the 2006 MEPS respondents, 34,091 participants had no medical record of HIV/AIDS. Among these HIV seronegative respondents 5,745 respondents belonged to the age group of 2-15 yrs. Four children from this had HIV seropositive parents hence were excluded from the group, thus we had a group of 5,741 uninfected children living with HIV seronegative parent(s). Since we had collected the primary data from Memphis, Tennessee, respondents in the MEPS database who belong to the southern region was considered. From the 5,741 respondents, 2,194 children belonged to the southern region of US as defined by MEPS.

Propensity score matching was done with 98 participants in the primary group and 2,194 participants in the comparative group. Upon matching, 89 participants from the primary group matched with 178 participants in the comparative groups (1:2 ratio), thus

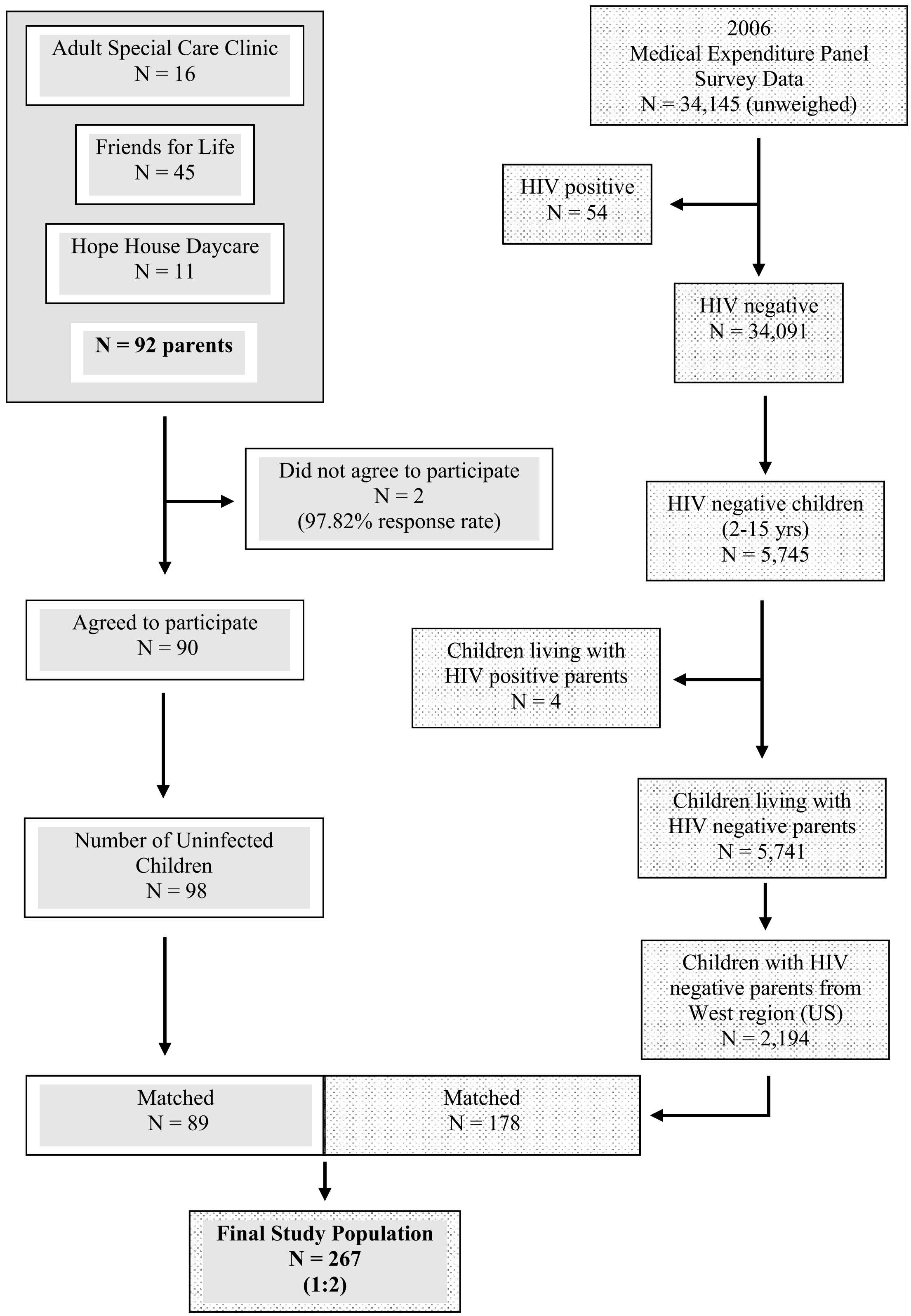


Figure 4-1: Schematic representation of the data collection and data mining process

making the final study sample of 267 participants. Nine participants were did not had a match hence were excluded from the study analysis.

4.1.2 Demographic and Socioeconomic Characteristics

After matching, 89 children (33.33%) who live with their HIV seropositive parent(s) and 178 children (66.66%) who live with their HIV seronegative parent(s) made up the final study population for analysis.

Table 4-1 summarizes the age, gender, race, ethnicity, annual family income and insurance status of the children considered for final analysis. Table 4-1 also provides information on the parent's age and gender, parent's educational status, and parent's marital as well as insurance status of each child included in the study analysis.

4.1.2.1 Child Related Factors

The mean age for the children with HIV seropositive parent(s) was 8.47yrs (SD 4.45). Among them, 24.72% (n=22) were aged less than 5yrs, 34.83% (n=31) were aged between 5-9yrs, and 40.45% (n=36) were aged between 10-15yrs. The mean age for the children with HIV seronegative parent was 8.94yrs (SD 4.74) and 25.84% (n=46), 29.21% (n=52), and 44.94% (n=80) belonged to the age groups less than 5yrs, 5-9yrs, 10-15yrs, respectively. Among the children with HIV seropositive parent(s), 57.30% (n=51) were males, while 47.19% (n=84) of the children with HIV seronegative parent(s) were males. In terms of race, 91.01% (n=81) of the children with HIV seropositive parent(s) and 85.96% (n=153) were African American, while the rest in both the groups were Caucasian whites. Almost 97.75% (n=87) and 93.26% (n=172) of the children with HIV seropositive and seronegative parent(s) were non-Hispanics, respectively. Analysis of the annual family income of the study participants between the children with HIV seropositive and HIV seronegative showed that 59.55% (n=53) versus 45.51% (n=81) had income less than $10,000, 23.60% (n=21) versus 36.52% (n=65) had income between $10,000 - $20,000, and 16.85% (n=15) versus 17.98% (n=32) has income more than $20,000, respectively. Among these children, 78.65% (n=70) of those living with a HIV seropositive parent(s) and 85.39% (n=152) of those living with a HIV seronegative parents belong to single parent family.

4.1.2.2 Parent Related Factors

The mean age for the HIV seropositive parents were 33.57yrs (SD 7.78). Among them, 10.11% (n=9) were aged less than 25yrs, 80.90% (n=72) were aged between 25-44yrs, and 8.99% (n=8) were aged above 44yrs. The mean age for the HIV seronegative parents were 34.21yrs (SD 9.13) and 11.24% (n=20), 29.21% (n=52), 79.21% (n=141) and 9.55% (n=17) belonged to the age groups less than 25yrs, 55-44yrs, and above 44yrs, respectively. Among the children with HIV seropositive parent(s), 92.13% (n=82) had a

Table 4-1: Baseline characteristics of the study population (children of HIV seropositive versus seronegative parents)

Variables	Children of HIV seropositive parent		Children of HIV seronegative parent		P value
	Numbers	*%*	*Numbers*	*%*	
Study Population	98	4.27	2197	95.72	
Matched Population	89	33.33	178	66.66	
Age					0.6265
Less than 5 yrs	22	24.72	46	25.84	
5 - 9 yrs	31	34.83	52	29.21	
10 - 15 yrs	36	40.45	80	44.94	
Mean (SD)	8.47 (4.45)		8.94 (4.74)		
Minimum	2yrs		2yrs		
Maximum	15 yrs		15 yrs		
Sex					0.1192
Male	51	57.30	84	47.19	
Race					0.2367
Black	81	91.01	153	85.96	
White	8	8.99	25	14.04	
Ethnicity					0.1204
Non-Hispanics	87	97.75	166	93.26	
Parent's Age					0.9464
Less than 25 years	9	10.11	20	11.24	
25 - 44 years	72	80.90	141	79.21	
Above 44 years	8	8.99	17	9.55	
Mean (SD)	33.57 (7.78)		34.21 (9.13)		
Minimum	21yrs		19yrs		
Maximum	62yrs		67yrs		
Parent's Sex					0.6499
Females	82	92.13	161	90.45	
Parent's Marital Status					0.1654
Single	70	78.65	152	85.39	

Table 4-1 (Continued)

Variables	Children of HIV seropositive parent		Children of HIV seronegative parent		P value
	Numbers	***%***	***Numbers***	***%***	
Annual Family Income					0.0655
Less than $10,000	53	59.55	81	45.51	
$10,000 - $20,000	21	23.60	65	36.52	
Above $20,000	15	16.85	32	17.98	
Parent's Insurance Status					0.7227*
Insured	87	97.75	172	96.63	
Parent's Educational Status					0.3854
Less than 12 years	74	83.15	140	78.65	
Doctor Visits					0.0486
Mean (SD)	2.337 (2.39)		1.707 (2.52)		
Minimum	0		0		
Maximum	12		21		
Hospital Visits					0.0460
Mean (SD)	0.168 (0.54)		0.044 (0.25)		
Minimum	0		0		
Maximum	4		2		
ER Visits					0.2221
Mean (SD)	0.404 (0.80)		0.286 (0.58)		
Minimum	0		0		
Maximum	6		3		
School/Daycare Days Missed					
Mean (SD)	3.078 (3.58)		2.606 (4.91)		0.3734
Minimum	0		0		
Maximum	15		29		

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.
* Fisher Exact Test Two-sided Probability

seropositive mother, while 90.45% (n=161) of the children with HIV seronegative parents had a seropositive mother. Almost 97.75% (n=87) of the children with HIV seropositive parent had a parent with health insurance, while 96.63% (n=172) of the children with HIV seronegative parent(s) has a parent with health insurance. In terms of the level of education of the parent, 83.15% (n=74) and 78.65% (n=140) of the children with HIV seropositive and seronegative parent(s) had an education of less than 12 yrs, respectively.

4.1.2.3 Statistical Differences between Groups at Baseline

The Chi Square analysis showed that both the groups of children has no statistical difference in terms of age (p=0.6265), gender (p=0.1192), race (p=0.2367), ethnicity (p=0.1204), parent's age (p=0.9464), parent's gender (p=0.6499), parent's marital status (p=0.1654), family's annual income (p=0.0655), parent's insurance (p=0.6117) and parent's level of education (p=0.3854).

4.2 Inferential Statistics

4.2.1 Results for Aim 1

To determine whether HIV seronegative children living with HIV seropositive parent(s) have lower healthcare access in comparison to the HIV seronegative children living with HIV seronegative parent(s).

4.2.1.1 Hypothesis 1

Smaller proportion of children living with HIV seropositive parent(s) have a health insurance compared to children living with HIV seronegative parent(s).

Upon analysis, 97.75% (n=87) of the children living with a HIV seropositive parent(s) had health insurance. Out these 87 children, 84 (96.55%) children had a publicly funded insurance. Among the children living with a HIV seronegative parent(s), 96.63% (n=172) had health insurance and 77.9% (n=134) children of these had a publicly funded insurance. Fischer Exact Test analysis showed no statistical differences in the insurance status of the children in the two groups (p=0.6117). However, the proportional of children with a public insurance was significantly higher among those living with a HIV seropositive parent(s) (p=0.001).

The health insurance status of the children in the study population is summarized in Table 4-2.

Table 4-2: Insurance status of the study population (children of HIV seropositive versus seronegative parents)

Variables	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	*%*	*Numbers*	*%*	
Insurance Status					
Insured	87	97.75	172	96.63	0.7227*
Type of Insurance					
Publicly insured	84	96.55	134	77.91	<0.0001*

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.
* Fisher Exact Test Two-sided Probability

4.2.1.2 Hypothesis 2

Smaller proportion of children living with HIV seropositive parent(s) have a regular source of care compared to children living with HIV seronegative parent(s).

Almost 87.64% (n=78) of children, according to their HIV seropositive parent, reported to have a regular source of care (particular doctor's office) where the child is taken whenever the child is sick or when the parents need a medical advice, 3.37% (n=3) said they had more than one place, while 8.99% (n=8) children had no regular source of care. Responding to the same question, 86.68% (n=154) of the children with HIV seronegative parent confirmed having a regular source of care. None of children in the comparative group had more than one regular source of care. However, 12.36% (n=22) had no regular source of care. Chi Square analysis indicated no statistical differences between the groups (p=0.4453).

The responses of the study participants to the question on whether they had a regular source of care for the children are summarized in Table 4-3.

4.2.1.3 Hypothesis 3

Smaller proportion of children living with HIV seropositive parent(s) have a prescription drug insurance compared to children living with HIV seronegative parent(s)

As per the respondent, 95.51% (n=85) of the children with HIV seropositive parent(s) had a prescription drug insurance compared to 16.29% (=29) of the children with HIV seronegative parent(s).

Table 4-3: Regular source of care among the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	*%*	*Numbers*	*%*	
Regular Source of Care					0.4453
Yes	78	87.64	154	86.68	
No	8	8.99	22	12.36	
More than one place	3	3.37	0	-	
Missing	-	-	2	1.12	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.

The Fischer Exact Test indicate a significant difference between the two groups (p=<0.0001). Refer to Table 4-4 for a summary of the children having a prescription drug insurance coverage as a part of their health insurance plan.

4.2.1.4 Hypothesis 4

Higher proportion of children living with HIV seropositive parent(s) take more than 15 minutes to get to a healthcare provider compared to children living with HIV seronegative parent(s).

Only 14.61% (n=13) children living with a HIV seropositive parent(s) took less than 15 minutes to get to a healthcare provider versus 45.51% (n=81) of the children living with a HIV seronegative parent(s). Among children with HIV seropositive and seronegative parent(s), 53.93% (n=48) versus 34.27% (n=61), 26.97% (n=24) versus 6.74% (n=12) and 4.49% (n=4) versus 0% (n=0) took 15-30 minutes, 31-60 minutes, and more than 60 minutes, respectively, to get to their healthcare provider. Therefore, significantly more time is taken by the children of seropositive parent(s) to reach to their provider compared to the children of seronegative parents (p=<0.0001).

Majority of the children of seropositive as well as seronegative parent(s) are driven (72.28% versus 82.59%) or use a taxi (5.62% versus 3.93%) to get to their healthcare provider. However, 16.85% (n=15) of the children living with HIV seropositive parent(s) use public transport (bus or train), while 2.25% (n=2) had to walk to reach their healthcare providers. Also, both groups were significantly different in terms of their mode of transportation (p=<0.0001).

Table 4-5 summarizes the frequency distribution of time taken and the mode of transportation by the study participants to get to their healthcare provider.

Table 4-4: Prescription drug insurance of the study population (children of HIV seropositive versus and seronegative parents)

Variable	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	*%*	*Numbers*	*%*	
Prescription Drug Insurance					<0.0001*
Yes	85	95.51	29	16.29	
No	4	4.49	149	83.71	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.
* Fisher Exact Test Two-sided Probability

Table 4-5: Time and mode of transport taken to get to a provider among the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	*%*	*Numbers*	*%*	
Time Taken					<0.0001
Less than 15 minutes	13	14.61	81	45.51	
15 - 30 minutes	48	53.93	61	34.27	
31 - 60 minutes	24	26.97	12	6.74	
60 - 90 minutes	4	4.49	0	0	
91-120 minutes	0	0	0	0	
More than 120 minutes	0	0	0	0	
Missing	-	-	24	13.48	
Mode of Transport					<0.0001
Drives	0	0	0	0	
Is driven	67	72.28	147	82.59	
Taxi	5	5.62	7	3.93	
Public transport	15	16.85	0	0	
Walks	2	2.25	0	0	
Missing	-	-	24	13.48	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.
* Fisher Exact Test Two-sided Probability

4.2.1.5 *Hypothesis 5*

Higher proportion of children living with HIV seropositive parent(s) indicate having difficulty in getting to a healthcare provider compared to children living with HIV seronegative parent(s).

According to parent reported information, 4.49% of the children living with a HIV positive parent(s) found it very difficult (n=4) and 23.6% (n=21) found it somewhat difficult to get to a provider compared to 2.25% (n=4) and 2.25% (n=4) of the children who live with their HIV seronegative parent(s). Also, between the children of HIV seropositive and seronegative parents, respectively, 32.58% (n=29) versus 19.66% (n=35) found it not too difficult, while 39.33% (n=35) versus 61.8% (n=110) found getting to their provider was not at all difficult. The Chi Square analysis showed significant differences between the two groups in terms of their degree of difficulty faced to get to their provider (p=<0.0001).

Table 4-6 summarizes the responses of the study participants on the level of difficulty to get to a healthcare provider.

4.2.2 *Results for Aim 2*

To determine if HIV seronegative children living with HIV seropositive parent(s) have higher healthcare utilization in comparison to the HIV seronegative children living with HIV seronegative parent(s).

A logistic regression was performed to test the various hypothesis using a dichotomous dependent variable, respective to the hypothesis, and the child's HIV status of the parent as the independent variable adjusting for all the child and parent's predisposing, need and enabling factors, such as age, gender, race, ethnicity and insurance status of the child and the parent, annual family income, marital status of the parent, level of parent's education, number of dependents, health condition of the child, level of difficulty and time taken in getting to a healthcare provider, and usual source of care status.

A generalized linear regression using a negative binomial model was used to analyze the difference in the annual number of times the healthcare resource (doctor, hospital and emergency room visit) was utilized.

4.2.2.1 *Hypothesis 6*

Children of HIV seropositive parent(s) have lower likelihood for a doctor visit compared to children of HIV seronegative parent(s).

Table 4-6: Difficulty in getting to a provider among the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	*%*	*Numbers*	*%*	
Difficulty in Getting to a Provider					<0.0001
Very difficult	4	4.49	4	2.25	
Somewhat difficult	21	23.6	4	2.25	
Not too difficult	29	32.58	35	19.66	
Not at all difficult	35	39.33	110	61.8	
Missing	-	-	25	14.14	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.
* Fisher Exact Test Two-sided Probability

4.2.2.1.1 Results of Bivariate Analysis

Children of HIV seropositive parent have a mean number of doctor visits of 2.337, while the children of HIV seronegative parent have a mean of 1.707 numbers of visits to a doctor in the past 12 months (Table 4-7). The bivariate chi square analysis showed both these means to be significantly different (p=0.0486).

4.2.2.1.2 Results of Logistic Regression Model

The dependent variable for analyzing this hypothesis was whether the child had a doctor/physician visit in the past 12 months. The variable was dichotomized as ‘yes’ and ‘no’. Logistic regression estimates showed that children living with a HIV seropositive parent(s) were 1.682 times (95% CI: 1.115 – 6.453) more likely to have a doctor visit than the children living with a HIV seronegative parent after adjusting for all the child and parental predisposing, need and enabling factors. All the other factors were statistically insignificant except the age of the child. With every one year increase in the child’s age the likelihood of having a doctor visit decreased by 0.902 times (95% CI: 0.820 – 0.992).

The regular source of care (OR: 6.479; 95% CI: 0.979 – 42.861) was marginally significant (p<0.10). Please refer to Table 4-8 for the complete result of the logistic regression. The Max-rescaled R-square statistics for this model was 16.32% and the Hosmer and Lemeshow Goodness-of-fit test was 0.6832, which meant we failed to reject the null hypothesis and concluded that the model fits the data. The C statistics was 0.722 which means that for 72.20% of all possible pairs of children (one being those who had a

Table 4-7: Bivariate chi-square analysis of the number of doctor visits in the past 12 months for the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)	Children of HIV seronegative parents	P value
Doctor Visits			0.0486
Mean (SD)	2.337 (2.39)	1.707 (2.52)	
Minimum	0	0	
Maximum	12	21	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.

Table 4-8: Odd ratios from the logistic regression of the visit to a doctor/physician's office as the dependent variable

Variables	Doctor visit		
	Odd ratio	***95% CI***	***P value***
Children of HIV Parent	2.682	1.115 – 6.453	**0.0276**
Child's Age	0.902	0.820 – 0.992	**0.0340**
Parent's Age	1.015	0.965 – 1.068	0.5605
Child's Gender			
Male	0.640	0.338 – 1.211	0.1700
Parent's Gender			
Male	2.992	0.650 – 13.768	0.1593
Race			
Black	0.415	0.123 – 1.403	0.1570
Annual Family Income			
Less than $10,000	Reference	-	-
$10,000 - $20,000	2.021	0.924 – 4.423	0.0782
More than $20,000	0.962	0.359 – 2.575	0.9386
Marital Status			
Single	Reference	-	-
Married	1.748	0.628 – 4.869	0.2853

Table 4-8 (Continued)

Variables	Doctor visit		
	Odd ratio	***95% CI***	***P value***
Level of Education			
12 years or less	Reference	-	-
More than 12 years	0.967	0.407 – 2.295	0.9386
Child's Insurance Status			
Uninsured	Reference	-	-
Insured	1.047	0.082 – 13.304	0.9717
Parent's Insurance Status			
Uninsured	Reference	-	-
Insured	0.378	0.042 – 3.423	0.3872
No. of Dependents	0.940	0.612 – 1.444	0.7766
Health Condition			
Excellent/Good health	Reference	-	-
Worst/Bad health	2.051	0.733 – 5.742	0.1713
Access to Health Provider			
Not difficult at all	Reference	-	-
Not too difficult	1.339	0.596 – 3.011	0.4796
Somewhat or very difficult	0.528	0.184 – 1.513	0.2342
Time to Reach the Provider			
Less than 15 minutes	Reference	-	-
15 - 30 minutes	1.037	0.500 – 2.150	0.9220
More than 30 minutes	1.749	0.562 – 5.439	0.3341
Having a Usual Source of Care			
No	Reference	-	-
Yes	6.479	0.979 – 42.861	0.0526

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.

doctor/physician visit in the past 12 months and the other with no doctor visits) the model correctly assigned a higher probability to those who made a doctor visit in the past 12 months.

4.2.2.1.3 Results of Negative Binomial Regression Model

The dispersion parameter for this model was 1.693 (95% CI: 1.389 – 2.071), hence the data fits the negative binomial model.

The dependent variable was a count variable consisting of number of times the child has made a visit to a doctor/physician's clinic in the past 12 months. The regression model estimated that children living with HIV seropositive parent(s) have 49% (p=0.0206) more visits to a doctor than the children living with HIV seronegative parent(s). Also, children with an annual family income between $10,000 and $20,000 visit the doctor 72% (p=0.0008) more than the children who have a family income of less than $10,000 per year. Children with perceived worst/bad health condition visited the doctor 87% more than the number of visits made by children with an excellent/good perceived health condition. Children who found it not too difficult to get to their healthcare provider made 44% more visits to their provider than the number of visits made by the children who found it not at all difficult to get to their healthcare provider. And children who reported to take 15 – 30 minutes to reach to their healthcare provider visited a doctor 0.10 times more compared to the children who took less than 15 minutes to get to their provider. Table 4-9 summarizes the results of the negative binomial regression with doctor visits as the dependent variable.

The marital status of the parent (Rate Ratio: 1.4767; p=0.0639), number of dependents (Rate Ratio: 0.8368; p=0.0603) and regular source of care (Rate Ratio: 2.685; p=0.0691) were marginally significant (p<0.10).

4.2.2.2 Hypothesis 7

Children of HIV seropositive parent(s) have higher likelihood for a hospital visit compared to children of HIV seronegative parent(s).

4.2.2.2.1 Results of the Bivariate Analysis

The bivariate analysis showed that the mean number of hospital visits made by the children of HIV seropositive parent was significantly higher than that of the mean number of hospital visits observed among children of HIV seronegative parent (0.168 versus 0.044, p=0.0460), see Table 4-10.

Table 4-9: Rate ratios from the negative binomial regression of the visit to a doctor/physician's office as the dependent variable

Variables	Doctor visit	
	Rate ratio	***P value***
Children of HIV Parent	1.4920	**0.0206**
Child's Age	0.9707	0.1264
Parent's Age	1.0111	0.3004
Child's Gender		
Male	0.9385	0.6631
Parent's Gender		
Male	0.9804	0.9446
Race		
Black	0.7533	0.1829
Annual Family Income		
Less than $10,000	Reference	-
$10,000 - $20,000	1.7281	**0.0008**
More than $20,000	1.1849	0.4340
Marital Status		
Single	Reference	-
Married	1.4767	0.0639
Level of Education		
12 years or less	Reference	-
More than 12 years	0.7755	0.1858
Child's Insurance Status		
Uninsured	Reference	-
Insured	1.3200	0.6449
Parent's Insurance Status		
Uninsured	Reference	-
Insured	0.6889	0.2822
No. of Dependents	0.8368	0.0603

Table 4-9 (Continued)

Variables	Doctor visits	
	Rate ratio	***P value***
Health Condition		
Excellent/Good health	Reference	-
Worst/Bad health	1.8752	**0.0010**
Access to Health Provider		
Not difficult at all	Reference	-
Not too difficult	1.4454	**0.0346**
Somewhat or very difficult	0.9288	0.7715
Time to Reach the Provider		
Less than 15 minutes	Reference	-
15 - 30 minutes	1.1035	0.5569
More than 30 minutes	1.2614	0.3432
Having a Usual Source of Care		
No	Reference	-
Yes	2.6185	0.0691

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

Table 4-10: Bivariate chi-square analysis of the number of hospital visits in the past 12 months for the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)	Children of HIV seronegative parents	P value
Hospital Visits			0.0460
Mean (SD)	0.168 (0.54)	0.044 (0.25)	
Minimum	0	0	
Maximum	4	2	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.

4.2.2.2.2 Results of Logistic Regression Model

The dependent variable for analyzing this hypothesis was whether the child had a hospital visit in the past 12 months. The variable was dichotomized as ‘yes’ and ‘no’. Logistic regression estimates showed that children living with a HIV seropositive parent(s) had a higher likelihood (OR: 4.027; 95% CI: 0.811 – 20.00) of having a hospital visit than the children living with a HIV seronegative parent(s) after adjusting for all the child and parent’s predisposing, need and enabling factors. However, this relationship was statistically insignificant with a p value of 0.0885. All the other factors were statistically insignificant except for those who felt not too difficult to get to their healthcare provider. Child whose parents indicated that they did not find it too difficult to get to a provider were 6.588 times (95% CI: 1.143 – 37.969) more likely to have a hospital visit compared to those children whose parents indicated they did not find it difficult at all to reach a healthcare provider. Refer to Table 4-11 for the complete output of the logistic regression using the hospital visits as the dependent variable.

The Max-rescaled R-square statistics for this model was 34.47% and the Hosmer and Lemeshow Goodness-of-fit test was 0.8386, which meant we failed to reject the null hypothesis and concluded that the model fits the data. The C statistics was 0.879 which means that for 87.90% of all possible pairs of children (one being those who had a hospital visit in the past 12 months and other with no hospital visit) the model correctly assigned a higher probability for those who made a hospital visit in the past 12 months.

4.2.2.2.3 Results of Negative Binomial Regression Model

The dispersion parameter for this model was 0.778 (95% CI: 0.778 – 0.778), hence the data fits the negative binomial model.

The dependent variable was a count variable consisting of number of times the child has made a visit to a hospital in the past 12 months. The regression model estimated that children living with HIV seropositive parent(s) have 3.0 times (p =0.0244) more hospital visits than the children living with HIV seronegative parent(s). Also, children with an annual family income between $10,000 and $20,000 visit the hospital 2.2 times (p=0.0391) more than the children who have a family income of less than $10,000 per year. The analysis also showed that with every one additional increase in the number of dependents the number of hospital visits decreased by almost 63% (p=0.0129). And those who indicated that they had somewhat or very difficulty in getting to a healthcare provider has a thrice (p=0.0270) the number of hospital visits compared to those children whose parents found it not at all difficult in getting to a healthcare provider.

Table 4-12 summarizes the complete results of the negative binomial regression model for the number of hospital visits.

Table 4-11: Odd ratios from the logistic regression of the visit to a hospital as the dependent variable

Variables	Hospital visit		
	Odd ratio	***95% CI***	***P value***
Children of HIV Parent	4.383	0.818 – 23.447	0.0844
Child's Age	1.107	0.919 – 1.333	0.2841
Parent's Age	0.953	0.863 – 1.053	0.3432
Child's Gender			
Male	3.295	0.777 – 13.976	0.1058
Parent's Gender			
Male	4.819	0.383 – 60.571	0.2253
Race			
Black	1.421	0.094 – 21.527	0.8000
Annual Family Income			
Less than $10,000	Reference	-	-
$10,000 - $20,000	1.448	0.318 – 6.599	0.6322
More than $20,000	1.619	0.222 – 11.794	0.6344
Marital Status			
Single	Reference	-	-
Married	3.207	0.324 – 31.727	0.3190
Level of Education			
12 years or less	Reference	-	
More than 12 years	0.073	0.003 – 1.564	0.0941
Child's Insurance Status			
Uninsured	Reference	-	-
Insured	>999.9	-	0.9867
Parent's Insurance Status			
Uninsured	Reference	-	-
Insured	>999.9	-	0.9802
No. of Dependents	0.306	0.105 – 0.886	**0.0290**

Table 4-11 (Continued)

Variables	Hospital visit		
	Odd ratio	***95% CI***	***P value***
Health Condition			
Excellent/Good health	Reference	-	-
Worst/Bad health	0.508	0.037 – 6.909	0.6107
Access to Health Provider			
Not difficult at all	Reference	-	-
Not too difficult	9.388	1.372 – 64.232	**0.0225**
Somewhat or very difficult	8.923	1.005 – 79.233	**0.0495**
Time to Reach the Provider			
Less than 15 minutes	Reference	-	-
15 - 30 minutes	0.78	0.127 – 4.795	0.7883
More than 30 minutes	1.047	0.140 – 7.850	0.9647
Having a Usual Source of Care			
No	Reference	-	-
Yes	1.093	0.050 – 23.705	0.9549

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.

Table 4-12: Rate ratios from the negative binomial regression of the visit to a hospital as the dependent variable

Variables	Hospital visit	
	Rate ratio	***P value***
Children of HIV Parent	4.0305	**0.0244**
Child's Age	1.0047	0.9453
Parent's Age	0.9842	0.6440
Child's Gender		
Male	0.9042	0.8436
Parent's Gender		
Male	1.7480	0.5935
Race		
Black	1.1735	0.8697
Annual Family Income		
Less than $10,000	Reference	-
$10,000 - $20,000	3.2424	**0.0391**
More than $20,000	2.1027	0.3905
Marital Status		
Single	Reference	-
Married	2.1231	0.3628
Level of Education		
12 years or less	Reference	-
More than 12 years	0.4117	0.3193
Child's Insurance Status		
Uninsured	Reference	-
Insured	4.8303	0.5595
Parent's Insurance Status		
Uninsured	Reference	-
Insured	3.5113	0.5108
No. of Dependents	0.3722	**0.0129**

Table 4-12 (Continued)

Variables	Hospital visit	
	Rate ratio	***P value***
Health Condition		
Excellent/Good health	Reference	-
Worst/Bad health	0.7136	0.7227
Access to Health Provider		
Not difficult at all	Reference	-
Not too difficult	2.5961	0.1845
Somewhat or very difficult	3.2233	**0.0270**
Time to Reach the Provider		
Less than 15 minutes	Reference	-
15 - 30 minutes	1.4614	0.5947
More than 30 minutes	0.9101	0.9060
Having a Usual Source of Care		
No	Reference	-
Yes	0.9399	0.9588

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable

4.2.2.3 Hypothesis 8

Children of HIV seropositive parent(s) have higher likelihood for an emergency room visit compared to children of HIV seronegative parent(s).

4.2.2.3.1 Results of Bivariate Analysis

The results of the bivariate analysis of the number of ER visits made during the last 12 months showed no significant differences in the mean number of ER visits between the children of HIV seropositive and seronegative parent (0.404 versus 0.286, p=0.2221), see Table 4-13.

4.2.2.3.2 Results of Logistic Regression Model

The dependent variable for analyzing this hypothesis was whether the child had an emergency room visit in the past 12 months. The variable was dichotomized as 'yes' and 'no'. Logistic regression estimates showed that children living with a HIV seropositive parent(s) had a higher likelihood (OR: 2.007; 95% CI: 0.900 – 4.476) for an emergency room visit in the past 12 months than the children living with a HIV seronegative parent(s) after adjusting for all the child's and parent's predisposing, need and enabling factors. However, this relationship was statistically insignificant with a p value of 0.0887. All the other factors were statistically insignificant, except the parent's insurance status. Children of insured parents were 0.185 less likely to visited an emergency room in the past 12 months compared to those children whose parents are not insured. For the summarized results of the logistic regression model for the emergency visits as the dependable variable please refer to Table 4-14.

Table 4-13: Bivariate chi-square analysis of the number of emergency room (ER) visits in the past 12 months for the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)	Children of HIV seronegative parents	P value
ER Visits			0.2221
Mean (SD)	0.404 (0.80)	0.286 (0.58)	
Minimum	0	0	
Maximum	6	3	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.
* Fisher Exact Test Two-sided Probability

Table 4-14: Odd ratios from the logistic regression of the visit to an emergency room as the dependent variable

Variables	Emergency room visit		
	Odd ratio	***95% CI***	***P value***
Children of HIV Parent	2.007	0.900 – 4.476	0.8691
Child's Age	0.953	0.868 – 1.046	0.0887
Parent's Age	1.002	0.953 – 1.054	0.3060
Child's Gender			
Male	1.747	0.908 – 3.359	0.9360
Parent's Gender			
Male	0.900	0.238 – 3.400	0.0947
Race			
Black	0.863	0.316 – 2.258	0.8760
Annual Family Income			
Less than $10,000	Reference		-
$10,000 - $20,000	1.129	0.547 – 332	0.7735
More than $20,000	0.790	0.272 – 2.294	0.7423
Marital Status			
Single	Reference	-	-
Married	0.666	0.246 – 1.805	0.4248
Level of Education			
12 years or less	Reference	-	
More than 12 years	0.631	0.245 – 1.622	0.3393
Child's Insurance Status			
Uninsured	Reference	-	-
Insured	0.979	0.073 – 13.120	0.9872
Parent's Insurance Status			
Uninsured	Reference	-	-
Insured	0.185	0.038 – 0.894	**0.0358**
No. of Dependents	0.959	0.626 – 1.468	0.8463

Table 4-14 (Continued)

Variables	Emergency room visit		
	Odd ratio	***95% CI***	***P value***
Health Condition			
Excellent/Good health	Reference	-	-
Worst/Bad health	1.369	0.556 – 3.374	0.4943
Access to Health Provider			
Not difficult at all	Reference	-	-
Not too difficult	0.885	0.393 – 1.993	0.7682
Somewhat or very difficult	0.795	0.267 – 2.263	0.6798
Time to Reach the Provider			
Less than 15 minutes	Reference	-	-
15 - 30 minutes	1.046	0.493 – 2.220	0.9060
More than 30 minutes	0.661	0.202 – 2.162	0.4939
Having a Usual Source of Care			
No	Reference	-	-
Yes	2.915	0.280 – 30.397	0.3711

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

The Max-rescaled R-square statistics for this model was 11.23% and the Hosmer and Lemeshow Goodness-of-fit test was 0.1274, which meant we failed to reject the null hypothesis and concluded that the model fits the data. The C statistics was 0.681 which means that for 68.10% of all possible pairs of children (one being those who had an emergency room visit in the past 12 months and the other with no

4.2.2.3.3 Results of Negative Binomial Regression Model

The dispersion parameter for this model was 1.314 (95% CI: 0.846 – 1.964), hence the data fits Poisson distribution instead of a negative binomial model (as the 9% CI includes 1).

The dependent variable was a count variable consisting of number of times the child has made a visit to an emergency room in the past 12 months. The Poisson regression model estimated that children living with HIV seropositive parent(s) have 86% (p =0.0464) more visits to an emergency room than the children living with HIV seronegative parent(s). All other variables in the model were found to be statistically insignificant.

Table 4-15 summarizes the results of the negative binomial regression model for the number of emergency visits.

4.2.3 Results for Aim 3

To determine the healthcare outcomes of the HIV seronegative children living with HIV seropositive parent(s) in comparison to HIV seronegative children living with HIV seronegative parent(s).

4.2.3.1 Hypothesis 9

Children of HIV seropositive parent(s) have higher likelihood to have a school/daycare day missed due to ill health compared to children of HIV seronegative parent(s).

4.2.3.1.1 Results of Bivariate Analysis

Bivariate analysis of the child's productivity in school/daycare showed that the differences in the mean number of school/daycare days missed due to illness in the past 12 months were statistically insignificant (3.078 versus 2.606, p=0.3734), see Table 4-16.

Table 4-15: Rate ratios from the poisson regression of the visit to an emergency room as the dependent variable

Variables	Emergency room visit	
	Rate ratio	***P value***
Children of HIV Parent	1.8606	0.0464
Child's Age	0.9412	0.1018
Parent's Age	1.0095	0.6388
Child's Gender		
Male	1.5129	0.1180
Parent's Gender		
Male	0.5850	0.3128
Race		
Black	0.5874	0.1175
Annual Family Income		
Less than $10,000	Reference	-
$10,000 - $20,000	1.2903	0.3714
More than $20,000	1.1002	0.8353
Marital Status		
Single	Reference	-
Married	0.5524	0.1514
Level of Education		
12 years or less	Reference	-
More than 12 years	0.7263	0.4123
Child's Insurance Status		
Uninsured	Reference	-
Insured	0.9878	0.9913
Parent's Insurance Status		
Uninsured	Reference	-
Insured	0.4626	0.1269
No. of Dependents	0.8935	0.5025

Table 4-15 (Continued)

Variables	Emergency room visit	
	Rate ratio	*P value*
Health Condition		
Excellent/Good health	Reference	-
Worst/Bad health	1.6578	0.1065
Access to Health Provider		
Not difficult at all	Reference	-
Not too difficult	0.6824	0.2499
Somewhat or very difficult	0.6544	0.3458
Time to Reach the Provider		
Less than 15 minutes	Reference	-
15 - 30 minutes	1.3742	0.2850
More than 30 minutes	0.7444	0.5680
Having a Usual Source of Care		
No	Reference	-
Yes	3.1456	0.2890

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

Table 4-16: Bivariate chi-square analysis of the number of school day(s) missed due to illness in the past 12 months for the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)	Children of HIV seronegative parents	P value
School/Daycare Day(s) Missed			
Mean (SD)	3.078 (3.58)	2.606 (4.91)	0.3734
Minimum	0	0	
Maximum	15	29	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference is observed.
* Fisher Exact Test Two-sided Probability

4.2.3.1.2 Results of Logistic Regression Model

The dependent variable for analyzing this hypothesis was whether the child had missed a school/daycare day visit in the past 12 months. The variable was dichotomized as ‘yes’ and ‘no’. Logistic regression estimates showed that children living with a HIV seropositive parent were less likely to have missed a school/daycare (OR: 0.938; 95% CI: 0.425 – 2.069) than the children living with a HIV seronegative parent(s) after adjusting for all the child’s and parent’s predisposing, need and enabling factors. However, this relationship was statistically insignificant with a p value of 0.8743. Child’s age, parent’s age, marital status of the parent and the number of dependents had a significant influence on the likelihood of the child missing a school/daycare due to illness. With every one year increase in the age of the child the likelihood of having missed school/daycare due to illness increases 0.201 times (95% CI: 1.088 – 1.327), however with every increase in the age of the parent the likelihood of the child to miss school/daycare is 0.902 times (95% CI: 0.857 – 0.950). Children who reported to have a usual source of care were less likely to miss school/daycare because of illness (OR: 0.073; 95% CI: 0.007 – 0.734) compared to those children who did not had any usual source of care.

For the complete regression results of the logistic model for missed school/day care due to illness, please refer to Table 4-17.

4.2.3.1.3 Results of Negative Binomial Regression Model

The dispersion parameter for this model was 5.748 (95% CI: 3.567 – 9.233), hence the data fits the negative binomial model.

The dependent variable was a count variable consisting of number of day(s) the child has missed the school or daycare because of illness in the past 12 months. The regression model estimated that children living with HIV seropositive parent(s) missed less number of school or daycare day(s) than the children living with HIV seronegative parent(s) and this estimate was statistically insignificant (RR: 0.7462; p=0.3114). The regression also estimated that with every increase in the age of the child the number of missed day(s) increased by 10% (p=0.0039). However, with every one year increase in the parent’s age it decreased by 5% (p=0.0011). Children who had a usual source of care missed 85% (p=0.0142) less number of school/daycare day(s) compared to children who reported that they had no regular source of care.

Table 4-18 summarizes the results of the negative binomial model for the number of school/daycare day(s) missed due to illness.

Children who took 15 – 30 minutes to get to a provider missed more school/daycare day(s) due to illness compared to those children who take less than 15 minutes to get to a healthcare provider. However, this estimate was marginally significant (RR: 1.5982; p=0.0582).

Table 4-17: Odd ratios from the logistic regression using missing a school/daycare day(s) due to illness as the dependent variable

Variables	Missed school/daycare day(s) due to illness		
	Odd ratio	***95% CI***	***P value***
Children of HIV Parent	0.938	0.425 - 2.069	0.8743
Child's Age	1.201	1.088 - 1.327	**0.0003**
Parent's Age	0.902	0.857 - 0.950	**<0.0001**
Child's Gender			
Male	0.660	0.355 - 1.227	0.1888
Race			
Black	1.569	0.562 - 4.379	0.3894
Annual Family Income			
Less than $10,000 pa	Reference		-
$10,000 - $20,000 pa	0.861	0.340 - 2.180	0.7526
More than $20,000 pa	0.722	0.308 - 1.691	0.4534
Level of Education			
12 years or less	Reference		
More than 12 years	2.134	0.926 - 4.921	0.0753
Health Condition			
Excellent/Good health	Reference		-
Worst/Bad health	0.438	0.127 - 1.505	0.1897
Access to Health Provider			
Not difficult at all	Reference		-
Not too difficult	0.923	0.382 - 2.229	0.8582
Somewhat or very difficult	0.818	0.270 - 2.479	0.7226
Time to Reach the Provider			
Less than 15 minutes	Reference		-
15 - 30 minutes	1.444	0.722 - 2.889	0.2983
More than 30 minutes	1.695	0.592 - 4.849	0.3255
Having a Usual Source of Care			
No	Reference		-
Yes	0.073	0.007 -0.734	**0.0262**

Table 4-17 (Continued)

Variables	Missed school/daycare day(s) due to illness		
	Odd ratio	***95% CI***	***P value***
Predicted Doctor Visits	1.577	0.926 - 4.921	0.1442
Predicted Hospital Visits	2.213	0.082 - 77.024	0.5977
Predicted ER Visits	2.514	0.286 - 22.076	0.4056

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

Table 4-18: Rate ratios from the negative binomial regression using missing a school/daycare day(s) due to illness as the dependent variable

Variables	School/daycare day(s) missed due to illness	
	Rate Ratio	***P value***
Children of HIV Parent	0.7462	0.3114
Child's Age	1.1037	**0.0039**
Parent's Age	0.9426	**0.0011**
Child's Gender		
Male	0.9976	0.9916
Race		
Black	1.2591	0.5591
Annual Family Income		
Less than $10,000 pa	Reference	-
$10,000 - $20,000 pa	0.6621	0.2213
More than $20,000 pa	0.7970	0.4738
Level of Education		
12 years or less	Reference	-
More than 12 years	0.9174	0.7795
Health Condition		
Excellent/Good health	Reference	-
Worst/Bad health	1.0161	0.9715

Table 4-18 (Continued)

Variables	School/daycare day(s) missed due to illness	
	Rate Ratio	***P value***
Access to Health Provider		
Not difficult at all	Reference	-
Not too difficult	0.8085	0.4779
Somewhat or very difficult	0.7248	0.4190
Time to Reach the Provider		
Less than 15 minutes	Reference	-
15 - 30 minutes	1.5982	0.0582
More than 30 minutes	1.5893	0.2574
Having a Usual Source of Care		
No	Reference	-
Yes	0.1488	**0.0142**
Predicted Doctor Visits	1.5055	0.0623
Predicted Hospital Visits	1.0959	0.8532
Predicted ER Visits	0.6121	0.4029

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

4.2.3.2 Hypothesis 10

Children of seropositive parent(s) have a higher likelihood to be overweight compared to children of HIV seronegative parent(s).

4.2.3.2.1 Results of Bivariate Analysis

Descriptive frequency distribution of the data based on the BMI categorization indicated that only 20.22% (n=18) of the children living HIV seropositive parent(s) had a normal weight compared to 31.46% (n=56) among children living with their HIV seronegative parent(s). Nearly 5.6% (n=5) and 5056% (n=45) of the children living with HIV seropositive parent(s) were underweight and overweight, respectively. Whereas, among the children living with HIV seronegative parent(s), 2.8% (n=5) and 23.03 (n=41) were found to under and overweight, respectively. Chi Square analysis indicated these differences to be statistically significant (p=0.0012) (Table 4-19).

4.2.3.2.2 Results of Logistic Regression Model

The dependent variable for analysis this hypothesis was whether the child's was categorized as overweight. The variable was dichotomized as 'yes' and 'no'. Logistic regression estimates showed that children living with a HIV seropositive parent(s) were 4.041 times (95% CI: 1.887 – 13.471) more likely to be an overweight child compared to children living with a HIV seronegative parent(s) after adjusting for all the child and parental predisposing, need and enabling factors. All the other factors were statistically insignificant, although variables 'having any health condition' (OR: 4.039; 95% CI: 0.890 – 18.339) and 'usual source of care' (OR: 10.203; 95% CI: 0.913 – 114.030) were marginally significant at the 0.10 level. Table 4-20 for the logistic regression estimates using overweight as the dependent variable.

The Max-rescaled R-square statistics for this model was 23.74% and the Hosmer and Lemeshow Goodness-of-fit test was 0.4501, which meant we failed to reject the null hypothesis and concluded that the model fits the data. The C statistics was 0.740 which means that for 74.00% of all possible pairs of children (one being those who were over-weight and the other who were not) the model correctly assigned a higher probability to those were overweight.

4.2.3.3 Hypothesis 11

Children of seropositive parent(s) have a higher likelihood of being currently on a prescription medication for any health condition (physical/behavioral), other than vitamins, compared to children of HIV seronegative parent(s).

Table 4-19: Children who are overweight among the study population (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	***%***	***Numbers***	***%***	
BMI Categories					0.0012
Underweight (Below 5th percentile)	5	5.61	5	2.8	
Normal (5th to 85th percentile)	18	20.22	56	31.46	
Overweight (Above 85th percentile)	45	50.56	41	23.03	
Missing	21	23.59	76	42.96	

Note: Level of significance was at 0.05, a p value greater than this means no statistical differences between the two groups.

Table 4-20: Odd ratios from the logistic regression of the children who are overweight as the dependent variable

Variables	Overweight		
	Odd ratio	***95% CI***	***P value***
Children of HIV Parent	0.938	0.425 - 2.069	0.8743
Child's Age	1.201	1.088 - 1.327	**0.0003**
Parent's Age	0.902	0.857 - 0.950	**<0.0001**
Child's Gender			
Male	0.660	0.355 - 1.227	0.1888
Race			
Black	1.569	0.562 - 4.379	0.3894
Annual Family Income			
Less than $10,000 pa	Reference		-
$10,000 - $20,000 pa	0.861	0.340 - 2.180	0.7526
More than $20,000 pa	0.722	0.308 - 1.691	0.4534
Level of Education			
12 years or less	Reference		
More than 12 years	2.134	0.926 - 4.921	0.0753

Table 4-20 (Continued)

Variables	Overweight		
	Odd ratio	***95% CI***	***P value***
Health Condition			
Excellent/Good health	Reference		-
Worst/Bad health	0.438	0.127 - 1.505	0.1897
Access to Health Provider			
Not difficult at all	Reference		-
Not too difficult	0.923	0.382 - 2.229	0.8582
Somewhat or very difficult	0.818	0.270 - 2.479	0.7226
Time to Reach the Provider			
Less than 15 minutes	Reference		-
15 - 30 minutes	1.444	0.722 - 2.889	0.2983
More than 30 minutes	1.695	0.592 - 4.849	0.3255
Having a Usual Source of Care			
No	Reference		-
Yes	0.073	0.007 -0.734	**0.0262**
Predicted Doctor Visits	1.577	0.926 - 4.921	0.1442
Predicted Hospital Visits	2.213	0.082 - 77.024	0.5977
Predicted ER Visits	2.514	0.286 - 22.076	0.4056

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

4.2.3.3.1 Results of Bivariate Analysis

Descriptive frequency distribution of the data based on the current status of prescription intake of the children in the study sample population indicated that 32.58% (n=29) of the children living HIV seropositive parent(s) were currently on some kind of prescription medication prescribed by a doctor, other than vitamins compared to 20.78% (n=37) among children living with their HIV seronegative parent(s). Chi Square analysis indicated these differences to be statistically significant (p=0.0451) (Table 4-21).

4.2.3.3.2 Results of Logistic Regression Model

The dependent variable for analysis this hypothesis was whether the child was currently on any prescription medication for any medical/behavioral condition. The variable was dichotomized as ‘yes’ and ‘no’. Logistic regression estimates showed that children living with a HIV seropositive parent(s) were less likely (95% CI: 0.143 – 2.042) to be prescribed a medication for any health reason than the children living with a HIV seronegative parent(s) after adjusting for all the child’s and parent’s predisposing, need and enabling factors. However, this relationship was statistically insignificant with a p value of 0.8343. All the other factors were statistically insignificant except annual family income greater than $20,000. A child of parents with an annual family income of more than $20,000 was 2.749 times (95% CI: 1.527 – 9.203) and) more likely to have prescription medication for any health reason, other than vitamins, compared to children with an annual family income less than $10,000.

Children whose travel time to get a provider is greater than 30 minutes are more likely to have a prescription medication (OR: 2.964; 95% CI: 0.983 – 8.941), however this relationship was only marginally significant (p=0.0537).

Table 4-21: Children who are currently on prescription medication for any health condition (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	***%***	***Numbers***	***%***	
Currently on Prescription Medication					0.0451
Yes	29	32.58	37	20.78	
No	60	67.42	137	76.96	
Missing	0	0	4	2.24	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference between the two groups.

Table 4-22 summarizes the results of the logistic regression model for responses on the currently prescribed medications for a health reason as a dependent variable.

The Max-rescaled R-square statistics for this model was 16.20% and the Hosmer and Lemeshow Goodness-of-fit test was 0.1768, which meant we failed to reject the null hypothesis and concluded that the model fits the data. The C statistics was 0.702 which means that for 70.20% of all possible pairs of children (one being those who are currently on prescription medication and the other with are not) the model correctly assigned a higher probability to those who are on prescription medication, other than vitamins.

4.2.3.4 Hypothesis 12

Children of seropositive parent(s) have a higher likelihood to being currently on a prescription medication for mental health condition compared to children of HIV seronegative parent(s).

4.2.3.4.1 Results of Bivariate Analysis

Descriptive frequency distribution of the data for the reason for the current intake of prescription among the children in the study sample population indicated that almost 62.06% (n=18) of the children living HIV seropositive parent(s) were currently prescription medication are due to mental health or behavioral reasons compared to 18.92% (n=7) among children living with their HIV seronegative parent(s). Whereas, only 34.48% (n=10) of the children with HIV seropositive parent(s) indicated that the medication was for a physical problem versus 81.08% (n=30) among children with HIV seronegative parent(s). Chi Square analysis indicated these differences to be statistically significant (p=0.0005) (Table 4-23).

4.2.3.4.2 Results of Logistic Regression Model

The dependent variable for analyzing this hypothesis was whether the child was currently on a prescription medication for a mental/behavioral health condition. The variable was dichotomized as ‘yes’ and ‘no’. Logistic regression estimates showed that children living with a HIV seropositive parent(s) were 4.520 times (95% CI: 1.503 – 20.276) more likely be on a prescription medication for a mental health reason than the children living with a HIV seronegative parent(s) after adjusting for all the child and parental predisposing, need and enabling factors. And this relationship was statistically significant with a p value of 0.0101. Apart from income variable, all other factors were statistically insignificant. Children with an annual family income more than $20,000 were 3.8 times (95% CI: 1.243 – 18.774) more likely to be currently on a prescription for mental health condition.

Table 4-22: Odd ratios from the logistic regression of the children who are and aren't currently on prescription medication for any health condition as the dependent variable

Variables	Prescription medication for any health condition		
	Odd ratio	***95% CI***	***P value***
Children of HIV Parent	0.918	0.413 - 2.042	0.8343
Child's Age	1.068	0.939 - 1.178	0.1858
Parent's Age	0.953	0.905 - 1.003	0.0648
Child's Gender			
Male	0.837	0.444 - 1.580	0.5838
Race			
Black	0.683	0.239 -1.955	0.4775
Annual Family Income			
Less than $10,000 pa	Reference		-
$10,000 - $20,000 pa	1.204	0.454 - 3.192	0.7090
More than $20,000 pa	3.749	1.527 - 9.203	**0.0039**
Level of Education			
12 years or less	Reference		
More than 12 years	0.721	0.306 - 1.698	0.4548
Health Condition			
Excellent/Good health	Reference		-
Worst/Bad health	2.686	0.792 - 9.106	0.1128
Access to Health Provider			
Not difficult at all	Reference		-
Not too difficult	1.23	0.504 - 3.000	0.6496
Somewhat or very difficult	1.399	0.452 - 4.333	0.5601
Time to Reach the Provider			
Less than 15 minutes	Reference		-
15 - 30 minutes	1.569	0.749 - 3.287	0.2324
More than 30 minutes	2.964	0.983 - 8.941	0.0537
Having a Usual Source of Care			
No	Reference		-
Yes	>999.9	-	0.9756

Table 4-22 (Continued)

Variables	Prescription medication for any health condition		
	Odd ratio	***95% CI***	***P value***
Predicted Doctor Visits	1.042	0.306 - 1.698	0.8878
Predicted Hospital Visits	0.428	0.042 - 4.389	0.4751
Predicted ER Visits	1.924	0.175 - 21.138	0.5924

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

Table 4-23: Children who are currently on prescription medication for any health condition (children of HIV seropositive versus seronegative parents)

Variable	Children of HIV seropositive parent(s)		Children of HIV seronegative parent(s)		P value
	Numbers	***%***	***Numbers***	***%***	
Type of Prescribed Medication					0.0005
Physical/Medical	10	34.48	30	81.08	
Behavioral	18	62.06	7	18.92	
Other	1	3.44	0	0	

Note: Level of significance was at 0.05, a p value greater than this means no statistical difference between the two groups.

Children with a perceived health condition of worst/bad also are more likely to be currently on a behavioral medication (OR: 5.649; 95% CI: 0.764 – 41.752) compared to those children with a perceived health condition of excellent/good. However, this relationship was marginally significant (p=0.0898).

The Max-rescaled R-square statistics for this model was 28.37% and the Hosmer and Lemeshow Goodness-of-fit test was 0.30.84, which meant we failed to reject the null hypothesis and concluded that the model fits the data. The C statistics was 0.821 which means that for 82.10% of all possible pairs of children (one being those who have a prescription medication for a mental health condition and the other no mental health condition) the model correctly assigned a higher probability to those who were currently on a prescription medication by a physician for a mental health reason.

Table 4-24 summarizes the results of the logistic regression obtained from the model using the information on the whether the children were prescribed any medication for a mental/behavioral health condition as the dependent variable.

4.3 Sensitivity Analysis

In total 9 children did not have any paired match during the process of matching and were excluded in the above analysis. In the sensitivity analysis these 9 children were included and logistic regression of the healthcare utilization and health outcome variables were performed. Sensitivity analysis showed no differences in the significance of the variables observed earlier except that of the hospital visits. In the sensitivity analysis, children of HIV seropositive parent were significantly associated with their likelihood to have a hospital visit in the past 12 months. A child living with a seropositive parent(s) is 6 times more likely (OR: 7.883, 95% CI: 1.641 – 37.878) to have hospital visit in comparison to a child living with a seronegative parent.

The comparison of the results from the logistic regression using the matched data and the sensitivity analysis has been summarized in Table 4-25.

Table 4-24: Odd ratios from the logistic regression of the children who are and aren't currently on prescription medication for any mental condition as the dependent variable

Variables	Prescription medication for any mental health condition		
	Odd ratio	***95% CI***	***P value***
Children of HIV Parent	5.520	1.503 - 20.276	**0.0101**
Child's Age	1.124	0.948 - 1.333	0.1781
Parent's Age	0.947	0.862 - 1.039	0.2494
Child's Gender			
Male	1.753	0.597 - 5.146	0.3073
Race			
Black	0.951	0.102 - 8.823	0.9646
Annual Family Income			
Less than $10,000 pa	Reference		-
$10,000 - $20,000 pa	2.202	0.412 - 11.770	0.3561
More than $20,000 pa	4.830	1.243 - 18.774	0.0230
Level of Education			
12 years or less	Reference		
More than 12 years	1.189	0.331 - 4.273	0.7909
Health Condition			
Excellent/Good health	Reference		-
Worst/Bad health	5.649	0.764 - 41.752	0.0898
Access to Health Provider			
Not difficult at all	Reference		-
Not too difficult	1.715	0.404 - 7.274	0.4645
Somewhat or very difficult	2.081	0.409 - 10.595	0.3775
Time to Reach the Provider			
Less than 15 minutes	Reference		-
15 - 30 minutes	0.894	0.243 - 3.290	0.8657
More than 30 minutes	3.018	0.586 - 15.550	0.1867

Table 4-24 (Continued)

Variables	Prescription medication for any mental health condition		
	Odd ratio	***95% CI***	***P value***
Having a Usual Source of Care			
No	Reference	-	-
Yes	999.9	-	0.9775
Predicted Doctor Visits	0.675	0.258 - 1.768	0.4235
Predicted Hospital Visits	0.827	0.074 - 9.253	0.8776
Predicted ER Visits	1.924	0.175 - 21.138	0.5924

Note: Level of significance was at 0.05, a p value greater than this means no statistical association between the dependent and the independent variable.

Table 4-25: Comparison of the results from the logistic regression using the matched data and the sensitivity analysis

Variables	Original group (N=267)		Combined group (N=276)	
	OR	***P value***	***OR***	***P value***
Doctor Visit	2.682	0.0276	2.695	0.0236
Hospital Visit	4.383	0.0844	7.883	0.0099
ER Visit	2.007	0.0887	2.085	0.0656
Missed School/Daycare Days	0.938	0.8743	0.973	0.9467
Overweight	5.041	0.0013	4.729	0.0013
Prescription Status	0.918	0.8343	0.943	0.8840
Prescription for Mental Health	5.520	0.0101	4.952	0.0010

CHAPTER 5: DISCUSSION

This chapter summarizes the findings of the study along with its limitations and conclusion. The discussion on the impact of HIV status of the parent as part of the study findings has been divided into three sections – impact on child's access to healthcare, impact on child's healthcare utilization of resources and impact on the child's health outcomes. Recommendations for future research are discussed at the end of this chapter.

The parent's role in the development and growth of a child is critical. Parents are the 'gatekeepers' and hence the decision-makers on issues related to the health of the child. Any factor that tends to impact the decision making ability of the parent will surely have an impact on the development and growth of the child. This study considered the HIV status of the parent as one such factor. In this study the investigators aimed at examining the impact of the parent's HIV status on healthcare access, healthcare utilization and health outcomes of their children residing with them. Studies have already identified some impacts of parent's health on the healthcare utilization and the health outcomes in children.[116,117] However, the current literature is devoid of information on the impact of HIV-infected parent's health status on their uninfected child in the context of the child's access, utilization and outcomes of the resources used. The prime reason for the absence of such studies is that this phenomenon of uninfected children living with their HIV seropositive parents has been recently experienced. A decade ago, HIV-infected individuals had a very short life expectancy and limited treatment options. Also, their children lived with other caregivers, such as grandparents, or landed up in foster care facilities, and even before the demise of their infected parent(s). Recent developments in antiretroviral therapy and continuous social awareness of the disease has not only improved the life expectancy of the infected individuals, but have also increased their quality of life. As a result, more and more HIV-infected parents are seen to opt for parenthood despite the knowledge of their HIV infection. This study adds immensely to the literature of parental health impacts on the child, especially among the HIV-infected population. Also, the findings of this study have provided crucial information that could lead to several research questions and thus augment future studies.

5.1 Impact of Parent's HIV Status on the Child's Access to Healthcare

This study concludes that the child's access to healthcare resources is severely hampered due to the HIV status of their parent(s). Access to healthcare, as defined by the Institute of Medicine, is "the timely use of personal health services to achieve the best possible health outcomes".[118,119] According to the various theoretical and empirical concepts having a health insurance and a regular source of care are key constructs of access to healthcare.[32,120] Also, the definition of access by IOM emphasizes the importance of time as a factor that influences one's access to healthcare resources. Therefore, this study looked at access to healthcare insurance, access to regular source of care, travel time to get to a provider and level of difficulty faced to get to a provider as the critical variables to analyze the child's access to healthcare.

5.1.1 Impact on Child's Access to Health Insurance

This study shows that the HIV seropositive status of the parents had no impact on access to health insurance for children. In fact, children of HIV seropositive parents were found to have higher access to prescription drug coverage in comparison to children of HIV seronegative parent(s). Increased emphasis on the awareness of HIV as a chronic disease and continuous government initiated programs that provide health insurance coverage to certain marginalized sections of the society can be one reason that explain this finding. As almost 85% of the study sample population belonged to a low-income category, i.e. had an annual family income of less than $20,000, hence they all were eligible for state funded health insurance policies. The study also found that a greater portion of children living with HIV seropositive parent(s) were covered under publicly funded insurance compared to those living with HIV seronegative parents. The fact that the HIV population is more exposed to various health related awareness programs than non HIV individuals and that all HIV individuals, once diagnosed, are eligible for government funded insurance seems to justify the high proportions of children living with HIV seropositive parent having a public health insurance and a prescription drug coverage. This finding also supports the observations reported in other studies where a high degree of association between the parent's insurance status and the child's insurance status was observed.[117,121] A study by Lambrew J M (2001) on the US population found that low- income people and people with chronic diseases were less likely to have a private insurance.[121] The study also highlighted the fact that among low-income parents, health insurance was a matter of concern and when parents were insured, there was a higher likelihood that their children will also be insured.[121] Based on this fact, since most HIV seropositive parents have government sponsored prescription drug coverage, it was found that their children had prescription drug insurance in place compared to children of HIV seronegative parents.

5.1.2 Impact on Child's Access to Regular Source of Care

No difference between the children of HIV seropositive and seronegative parents were observed in terms of their access to a regular source of care. Health insurance exhibits a critical role in access to health care services in the current healthcare system in the US. Hence having healthcare insurance ensures a regular source of care for the individual. Since in our study almost everyone had health insurance hence everyone had access to a regular source of care.

5.1.3 Impact on Child's Access to a Healthcare Provider

Children of HIV positive parent(s) took more time to get to a provider compared to children of HIV seronegative parents. The study concluded that these children also experienced greater difficulty in getting to a provider. It was also found that almost a quarter of the children of HIV seropositive parents had to rely on public transportation systems, or use a hired vehicle and some had to even walk to reach their regular source of care. This problem of transportation to avail healthcare was minimal among children living with their HIV seronegative parent as more than 80% of them owned a vehicle. As this study was conducted in the city of Memphis where the public transportation system is not well developed compared to other metropolitan cities in US the hindrances posed by it is understandable. Also the differences in the sources of data for the primary group and the comparative group, i.e. the primary group came from Memphis, US, while the comparative group came from the southern states in US, could have influenced this result. Longer travel time and absence of adequate mode of transportation may explain to a great extent why the HIV seropositive parents reported very or somewhat difficulty in getting to a healthcare provider in case of any medical need for their children compared to HIV seronegative parents.

5.2 Impact of Parent's HIV Status on the Child's Healthcare Utilization

Three variables measured the child's healthcare utilization: child's doctor visits, hospital visits and emergency room visits during the last 12 months. This study found that children of HIV seropositive parent(s) had significantly higher doctor visits and were more likely to make such visits compared to children of HIV seronegative parents. However, no difference in their likelihood for hospital visits and emergency rooms visits were observed.

5.2.1 Impact on Child's Visit to a Doctor

Being HIV seropositive exposes the infected parent to numerous opportunistic infections and health related ailments. Therefore HIV-infected parents themselves utilize a greater quantity of healthcare resources. Previous studies indicate that parent's utilization of healthcare resources significantly influences the utilization of resources by their children.[117,122] One such study documented that children were two to three times more likely to see a doctor if their parents had seen a doctor, and that parents having health insurance are more likely to seek care.[117] In this study similar results were observed among children of HIV seropositive parents. This may partly explain the study findings. One other possible explanation could be the observed phenomenon of 'defensive mothering' among parents suffering from life threatening chronic illnesses. Mothers suffering from serious medical and psychological illnesses have been found to make higher referrals to specialists, and expressed less willingness to accept medical assurances. Such mothers also tend to perceive the medical condition of their child as less healthy.[116] This reason could probably explain the high number of doctor visits among children living with their HIV seropositive parent(s) observed in this study, compared to children living with their HIV seronegative parent. Altman et al. (1987) found that children of families with members with disability had higher utilization of doctors visits compared to children of families without disability.[63] Since the results were adjusted for child's health status, family income and insurance status, the possibility of these variables influencing their healthcare utilization was excluded.

5.2.2 Impact on Child's Visit to a Hospital

In regards to hospital visits, no significant association was observed between the parent's HIV status and the child's likelihood for a hospital visit. However, its association with the number of hospital visits in the past 12 months was significant. These children had a higher number of hospital visits compared to children of HIV negative parents. The suggestive explanation seems to be that parent's HIV status did not influence the parent's decision to take their child to a hospital although it greatly influenced the subsequent visits if an earlier visit was made. Presence of fear and uncertainty among the HIV-infected mothers is obvious, and the perception among the mothers that their child's health less than normal may be the underlying reason. This also suggest that the initiation of the hospital visits for a child may be the result of the child's actual medical need, while children of HIV seropositive parent(s) were more prone to subsequent visits compared to those of HIV seronegative parents.

5.2.3 Impact on Child's Visit to an Emergency Room

This study found no association between the HIV status of the parent and the child's likelihood for an emergency room visits among the children. This result adds to the previous work by Lipstein et al. (2009) where similar results were observed among children of parents suffering from chronic diseases.[123] However, the binomial regression of the children having atleast one emergency room visit showed that children of HIV seropositive parent(s) had higher number of emergency room visits than the children of HIV seronegative parents. This finding is similar to that observed in the hospital utilization patterns among children of HIV-infected parents. It seems the perception of the parent regarding the health of their children, as explained by the concept of 'defensive mothering', may influence the child's utilization of healthcare services. Further research is required to understand the exact reasoning of these phenomena.

5.3 Impact of Parent's HIV Status on the Child's Health Outcomes

The health outcomes variables considered for this study were missed school/daycare days in the past 12 months, child's Body Mass Index (BMI) and the current prescription medication status of the child. Productivity of an individual in the work force is a variable generally used in economic literature as a measure of the health status. However, among children their productivity is measured by their performance in the school/daycare. Absenteeism is highly association with performance hence missed school/daycare days was considered as an indicator for the child's productivity. The BMI has been considered as one of the good and easily measurable indicators of child's health outcomes hence was a variable of interest in this study.[124] Evidence of consumption of prescription drugs indicates the presence of the medical condition for which the medication has been prescribed. Current intake of prescription medication for either physical or mental reason was taken as an indicator of the child's health outcomes.

5.3.1 Impact on Child's Productivity in School/Daycare

No differences were observed in the likelihood or number of missed school/daycare days among children living with HIV seropositive and seronegative parents. Thus from this study it was concluded that the HIV status of the parent did not impact the overall productivity of their children. Increase in the quality of life among HIV patients adhering to the HAART treatment in recent years is well documented.[125,126] Adherence to the HAART treatment is a prime factor for desired treatment outcomes and individuals with children have been found to be more serious in their adherence to the treatment guidelines. Since our study population was comprised of children in a family setting hence it is quite possible that most parents had optimal adherence to treatment guidelines. This study did not have adequate information on the parenting skills and disease coping skills of parent hence it limited interpretation of this study finding. Length of period the individual has been exposed to the disease plays a crucial role in the development of adequate coping skills. Since our study inclusion criteria considered children born to HIV-infected parent after the detection of the disease it is possible that these parents were mentally prepared and were more responsible or over cautious towards the health of their children. Another line of thought could be that HIV-infected parents prefer to send their kids to school/daycare irrespective of their health status as they are unable to provide the adequate attention and time demanded by a child when they stay at home.

This particular finding contradicted an earlier study that reported high number of school/daycare days missed due to illness among children living with parent suffering from chronic disease versus children living with parents with no chronic disease.[127] However, the previous study looked at children suffering from asthma and this criterion may have lead to the observed contradiction.

5.3.2 Impact on Child's Body Mass Index

Though the bivariate analysis showed a significant proportion of children living with HIV seropositive parent(s) are overweight, the multivariate logistic analysis showed no differences in the likelihood of a child of HIV seropositive parent(s) to be overweight compared to children of a HIV seronegative parent. Similar results were observed by studies done in European setting by Ross et al. (1995) and Newell et al. (2003).[19,20] Therefore, this study concludes that the HIV status of the parent does not impact the height and weight of the child residing with them. Agostoni et al. (1998) also reported no difference in the BMI of uninfected children in the first 6 months compared to the reference group born at the same hospital.[128] Growth faltering is dependent on various socio-economic and environmental variables and not just on the health status of the mother. Since both the groups compared in this study were similar in terms of their socio-economic variables the difference in their BMI was minimal. This finding was in agreement with other studies found in the literature.

5.3.3 Impact on Child's Prescription Drug Status

The information on the prescription drugs administered by the child other than vitamins during the study period provided crucial information on the presence of a medical or health condition. This information also assisted in understanding whether this medical condition was physical or behavioral in nature. This study concluded that the HIV status of the infected parent has no impact on the prescription drug status of the child. However, further subgroup analysis on the type of prescription drug administered by the child revealed that significantly higher proportion of children living with HIV seropositive parent(s) were on psychotropic medications compared to children living with HIV seronegative parents. This suggests that children of HIV seropositive parent(s) are vulnerable to severe mental and behavioral disorders. As this study considered the information on administered psychotropic medications as an indicator of mental health condition in a child, it is possible that this approach may have missed those children who may have mental health needs but currently were not on any kind of prescription medication. In this scenario, our study findings could have underestimated the presence of mental health needs in this population. The prevalence of mental health problems among children of parents with somatic illness has been well documented.[11,129-131] Several studies have reported the presence of emotional and behavioral problems among children of cancer patients, especially in their adolescent age.[68,132-134] Depression is one of the most common symptoms observed in chronically ill parents and an extensive personal limitations associated with depression among women is also well established.[67] Families of HIV-infected individuals are further exposed to alterations in daily family routines caused by regular hospital and physician visits which can be overwhelming for the children.[68] Social stigma is one big factor that burdens the infected person continuously and the impact of the disclosure of the parents HIV status on the children is enormous.

Concurrently, these findings need to be interpreted cautiously as some studies looking at the long term impacts of parental HIV status on their mental health of the child provide a different picture. A study by Murphy et al. (2006) found significant declines in degree of behavioral problems among children living HIV-infected mothers and that it was significantly associated with the health status of the parent at the time of entry in to the study.[135] In a pilot study, Pilowsky et al. (2001) revealed no significant differences in the psychopathological symptoms in children of HIV-infected versus non-HIV-infected parents.[89] This study did not take the severity of the HIV disease of the parent in to consideration and this could limit the strength of the conclusions. Also, several antisocial behavioral factors such as drug abuse, crime, unwanted sexual orientation, etc, in HIV parents, which are prevalent in the HIV-infected population and had the potential to bias the study result, were not considered in this study. It has been estimated that 40% of the HIV population has been a recent drug user and this could potential bias the results.[86] Numerous such factors prevalent among this population are required to be included to get the clear picture. Consequently, this study suggests further research to unearth the long term impacts of the parent's HIV status on their children.

5.4 Limitations

The study possesses certain limitations which may induce unobserved bias in to the analysis and some of these have been discussed below.

The study used a convenience sampling method to identify the HIV seropositive parents visiting the study sites. This method did not reach those HIV seropositive parents who were not encountered at the study sites during the period of study or those who are not associated with the study sites. Since the study sites address more than 80% of the HIV-infected population in and around the city of Memphis, TN, the investigator is confident that its impact on the final results was minimal. The findings of this study may not be generalized to the complete HIV/AIDS population in the US, but the study result represents HIV-infected populations similar to the study population used in this study.

The CDC report, 2008, estimates that almost 25% of the HIV-infected population was unaware of their HIV positive status. As the comparative group extracted from the MEPS database consisted of individuals having no previous record of an HIV infection and was not based on a HIV serological test. There is a possibility that the comparative groups may consists of HIV-infected parents who were unaware of their infection. Absence of a confirmatory serological test to identify HIV negative parents may limit the study results.

The information on the children living with HIV seropositive and seronegative parents were parent-reported information. The study assumed that the parents were well informed about the health of their child and hence provided the best answers to the questions posed to them during the interview process. The questionnaire used for this study was derived from the Child Health Questionnaire (CHQ), similar to the one used by MEPS in their data collection process.[104] The reliability and validity for the use of CHQ in HIV patient population has been well established in previous studies hence the effect of this limitation on the study finding is negligible.[136] Like all self reported studies, this study may also be subjected to recall bias as the data collected is based on self-reported events.

The information on the children of HIV seropositive was collected through a primary data collection procedure and the comparative data, i.e. information on children of HIV seronegative data, was obtained from the MEPS 2006 survey data. Since information on the groups compared was obtained from two different sources thus may induce certain observed and unobserved bias, apparent to observational studies, during the analysis of the study. However, the study used a propensity based matching technique before the analyses to ensure groups were as similar as possible and this attenuated the biases induced due to difference in their source. The use of this technique to reduce the observed and unobserved bias, generally experienced in observational studies, has been well established.[105,107,110]

5.5 Conclusion

The purpose of this study was to understand the impact of the parent's HIV seropositive status on the access to healthcare services, healthcare service utilizations and health outcomes in their uninfected children currently living with them. Upon analysis, several conclusions were derived and documented.

One of the main conclusions was that the HIV status of the parent affected their child's access to healthcare services. In traditional theoretical models health insurance is significantly linked to access to healthcare. The general thinking within the current health system is that if adequate health insurance is available, then the healthcare requirements of the children from culturally and traditionally diverse backgrounds can be met with this present system.[137] This line of thinking delineates the existence of several other institutional barriers such as public transportation policies, micro level family based barriers, education and ethnic sentiments, etc, that may dictate the child' access to healthcare in conjunction with health insurance. Health insurance is a key element to having an access to healthcare services but does not ensure adequate utilization of resources. This fact was highlighted from this study which showed that most children had health insurance in place, but absence of basic transportation hampered their timely utilization of basic healthcare services.

Another conclusion of this study was that these children have an over-utilization of health resources, especially with respect to visits to a physician. A high number of physician visits were observed among children living with HIV seropositive parent(s) in comparison to children of HIV seronegative parent(s). It seems that availability of the health insurance allowed accessing physician's services. However, this utilization could not be explained as the results of this study were adjusted for the health of the child. Also, no differences in the likelihood of utilization of hospital and emergency room services between the children of HIV-infected and non-infected parents negate the possibility of a disease induced demand for healthcare services. Presence of fear and apprehension that their child is not as healthy as other children or that their children may fall sick may have lead to this psychosis driven demand for healthcare resources. Information, education and communication have been identified as key drivers of successful public health policies and absence of these elements limit the adequate implementation and execution of a healthcare program. This study call for education and awareness programs which focus on the HIV-infected mothers related to parenting and child development skills.

Finally, this study concluded that the parent's HIV status did not impact the physical development of the child as no differences in the BMI of the child or absenteeism in the school/daycare were observed. However, the impact on psychological growth of the child was significant. Almost 60% of the children on prescription medications were taking them due to mental health reasons. This association needs to be seriously looked at as the presence of mental health problems among children of critically ill parents has been well documented. Children experiencing mental health problems during their childhood have been found to have diminished social, emotional and cognitive skills. They are more prone to be school dropouts, develop alcohol and illicit drug use, engage in anti-social activities, are more likely to be involved in juvenile crimes, develop suicidal tendencies and may result to an early death.[138-140]

The presence of mental health problems observed in this study can also be explained by the age group of the study population. The mean age of children in this study was around 8 years. Children of this age group (6 – 11 years) develop a sense of autonomy and have greater emotional independence.[141,142] This group of children separate easily from their parents and see themselves as autonomous individuals leading to initiation of their self-esteem/self-regard, in relationship to others.[141] This transition from early adolescence to middle adolescence plays a significant role in the degree of influence a parent may have on their children.[143] Responses of parents toward this personality shift among their children is crucial in the further development of the parent-child relationship. If the parent is unable to provide adequate attention to their child during this growth phase, which may arise because of depression, physical illness such as HIV/AIDS, or even due to illicit lifestyle behaviors, may have long term detrimental effects on the child's behavior. Some children may internalize these responses of their parent(s) as 'non-motivating' or 'disapproval' resulting in the child developing poor self-worth.[141] Parent(s) in this study were suffering from HIV/AIDS and the related diseases, and presence of behavioral and personality related limitation among this population is well established.[144-146] This limited attention and lack of motivational responses shown by HIV-infected parent(s) may turn the behavior of a child inward (depression, poor social skills, etc) or outward (bullying fighting, poor academic performance). Attending to the mental health needs among HIV patients through adequate interventions has also been recommended in various global HIV/AIDS initiatives such as the World Health Organization's '3 by 5' Initiative.[147] Further study is recommended to understand the role of different child's age groups and the age-specific psychological dynamics in manifesting the impact of parent's HIV status on their uninfected children.

5.6 Policy Implications

As this study was conducted on a restricted population, further research needs to be augmented to generalize the result to a larger population. However, certain key lessons were learned from this study which can have certain health policy implications. Most public sponsored programs targeted for the HIV population are individual centric and hence catering to the needs of HIV-infected individuals.[148] With the observed impacts of the parents HIV status on healthcare access, resource utilization and certain long term health outcomes from this study, it is necessary to move the current programs to a more family-centric approach. Current programs that facilitate healthcare resources to HIV-infected populations need to also include children and families affected by HIV. There is a need to design and implement interventions focusing on children's current unmet mental health needs among this at risk population.

This study also highlights the need for treatment guidelines especially for healthcare professionals providing medical care to children. Since this study showed a significant impact of the parent's HIV status on nutrition and mental health of the child, it becomes necessary for the parents to disclose their HIV status to their child's physician. Consequently, each physician needs to be aware of the parent's HIV status in order to make adequate treatment decisions regarding their child age patients. As a policy, it is suggested that each parent should be required to disclose their HIV status as a part of their child's medical history. Policy makers should ensure that this requirement be an integral part of the treatment guidelines for every health professional managing healthcare needs of the children of HIV patients.

5.7 Recommendations for Future Research

This study has brought to our attention issues relating to access to healthcare resources, lack of education and fear among HIV-infected parents, and impact of the parent's HIV status on the psychological development of the HIV affected child. In order to identify, design and implement adequate policies and programs that will provide education and enhance the awareness of the HIV-infected parents, policy makers and the healthcare community, a comprehensive research is required. Some of the recommendations for future researchers are as follows:

1. A study that has more generalizability to the HIV/AIDS population in the US should be augmented. This will help provide a comprehensive picture of the actual impact of parent's HIV status on their children. This will also enable the design of policies at the State and Federal level.
2. Since most of the study participants were African Americans and non-Hispanics, this study could not analyze the racial and ethnic disparities in its findings. Future research is required to understand the existence of any such variations in the impact in order to address it accordingly.
3. Geographical factors such as zip codes, type of city, state specific policies, etc were not considered in this study. Hence future research is recommended to understand the variations in results after adjusting for these factors.
4. Better understanding of the impact of parent's HIV status on the different age groups of children is necessary so that adequate policies can be made more specific during implementation.
5. This study looked into cross sectional or short-term impacts and therefore a study focusing on the long term impacts of the parent's HIV status on their children is recommended.
6. Variation in the impact of HIV status based on parent-specific factors such as HIV parents using illicit drugs or disclosure of their status to the children, etc, are specific questions a researcher may be interested in investigating in the future.

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APPENDICES

APPENDIX A: INTRODUCTION TO HIV/AIDS

A.1 History of HIV/AIDS

The history of HIV virus has been really fascinating. Serological evidences confirm that the virus has been in existence since 1959.[149] Zhu et al. (1998) found the strains of the HIV/AIDS virus in the blood sample obtained from an adult Bantu male, who died of an unexplainable disease in the Leopoldville region of Belgian Congo (now Kinshasa, Democratic Republic of Congo).[150] The first case of HIV diagnosed in the United States was reported among five gay men in the June 5, 1981, in their Morbidity and Mortality Weekly Report (MMWR), by the Center for Disease Control and Prevention (CDC).[151] This report identified this disease as a "cellular-immune dysfunction related to a common exposure" and a "disease acquired through sexual contact". Later, this virus was named 'Human Immunodeficiency Virus, commonly known as 'HIV'.

A.2 Human Immunodeficiency Virus Disease (HIV)

Human Immunodeficiency Virus was first isolated in 1983 from a patient with lymphadenopathy and was identified as the causative agent of Acquired Immunodeficiency Syndrome (AIDS) by 1984.[152] HIV represents the subfamily of lentiviruses (Lentivirinae) of the human retroviruses family (Retroviridae) and apart from human beings it infects mainly the vertebrates. The human retroviruses can be classified in to two groups: the human T lymphotropic viruses (HTLV-I and HTLV-II), which are transforming retroviruses, and the human immunodeficiency viruses (HIV-1 and HIV-2). HIV-1 and its subtypes are the most common cause of the infection seen throughout the world, and in the United States, while HIV-2 has been detected in several cases in West Africa or in cases with sexual contact with West Africans. Both the types are classified as zoonotic infection but HIV-1 is the main cause of the infection among human beings.

A.2.1 Morphology of the Virus

The view of the virus observed through an electron microscope reveals the icosahedral structure with several spikes on the external surface formed by the two main envelop proteins, the external gp120 and the transmembrane gp41 (Figure A-1).

Retroviruses measure 70 – 140 nm in diameter and consists of a lipid-containing envelop which surrounds the icosahedral capsid with a dense inner core. Within this core are two identical copies of single-strand RNA genome. The RNA genome is fused with reverse transcriptase and tRNA, and is 8-10 kb long. The virion particle also consists of other viral proteins, such as the integrase. Similar to the mRNA, virion RNA has a cap site at the 5' end of the RNA genome, which is important in the initiation of mRNA translation, and a polyadenylation site at the 3' end, which influences mRNA turnover. This feature cases messages with shorter polyA tails turn over faster then messages with longer polyA tails. However, there is no translation of the retroviral RNA, instead it is transcribed in to DNA, and this DNA form is called a *provirus*.

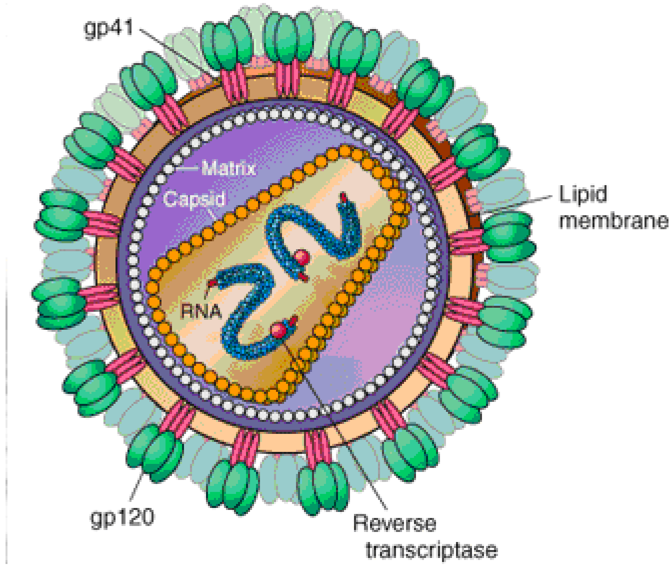


Figure A-1: Schematic structural representation of the HIV-1
(Reprinted with permission from McGraw Hill Companies, Inc®. Fauci AS, Lane CH. Human Immunodeficiency Virus Disease: AIDS and related disorder. In: Anthony S.Fauci, Dennis L.Kasper, Dan L.Longo et al, Eds. Harrison's Principles of Internal Medicine. 17th Edition. The McGraw-Hill Companies, Inc.; 2008:1137-1203.)[153]

A.2.2 Replication Cycle of HIV

The transformation of the genomic RNA to DNA in HIV is brought by the enzyme reverse transcriptase. The replication cycle of the HIV starts with the binding of the virus to the host cell surface, the CD4 molecule. This is done by the N terminus of the V1 region of the gp120 protein which has a high affinity for the cell surface. This facilitates the penetration of the gp41 in to the plasma membrane of the CD4 cell and then the coiling of this protein brings the virion and the target cell together. Once both these cell fuse it triggers the release of the protein coated capsid containing the viral RNA and the enzymes in to the cytoplasm of the target cell. Through the cytoplasm this complex capsid reaches the nucleus, and then the reverse transcriptase enzyme catalyzes the reverse transcription of the genomic RNA in to DNA. The protein coats break open thereby releasing the double-stranded HIV-DNA in to the host CD4 cell. The HIV provirus DNA with the help of the enzyme integrase integrates with the chromosomes of the host cell. At this stage the provirus may remain inactive (latent period) or may even manifest itself to actively produce more viruses. Further progression of the disease is dependent on the interaction of a number of cellular and viral factors. From the therapeutic point of view each stage of the replication cycle of the HIV is a potential target for pharmacologic intervention (Figure A-2).

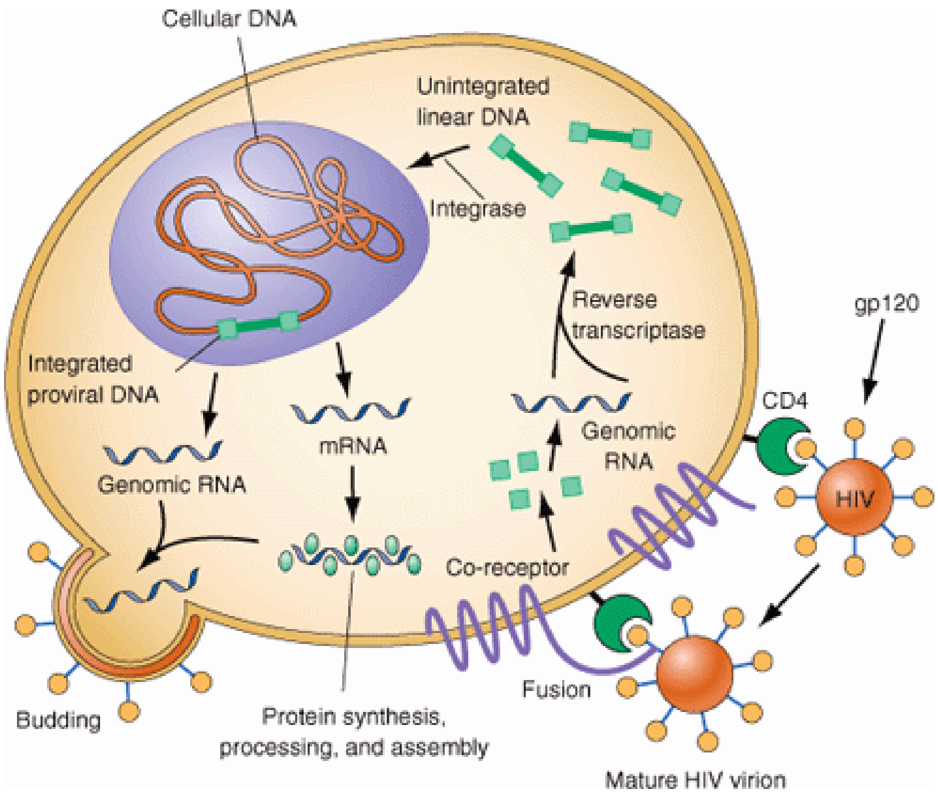


Figure A-2: The replication cycle of HIV
(Reprinted with permission from McGraw Hill Companies, Inc®. Fauci AS, Lane CH. Human Immunodeficiency Virus Disease: AIDS and related disorder. In: Anthony S.Fauci, Dennis L.Kasper, Dan L.Longo et al, Eds. Harrison's Principles of Internal Medicine. 17th Edition. The McGraw-Hill Companies, Inc.; 2008:1137-1203.)[153]

A.2.3 Transmission

HIV is a sexually transmitted disease and transmitted by both homosexual as well as heterosexual contact. Additionally, HIV can be transmitted by blood and blood products; and from mother to infant, either intrapartum, parentally, or via breast milk.[153] In United States, male-to-male sexual contact resulted in approximately 49% of the infection while the heterosexual sexual contact accounted for nearly 32% of new infection, rest through other non-sexual routes. Although worldwide, heterosexual contact is the most predominant cause for the spread of the disease. Among the non-sexual contact route of infection, infection because of sharing of paraphernalia such as needles, syringes or cottons is predominant. This is common among intravenous drug users (IDU) and individuals with hemophilia or other clotting disorders. In case of mother-to-child transmission of HIV infection the likelihood of the transmission is high in the perinatal stage. Studies done on the HIV mothers in Rwanda and Zaire showed 23-30% of the children were infected before birth (prenatal), 50-65% during birth, and 12-20% via breast feeding**.** Transmission of the HIV infection via saliva is yet to be evident.[153] Studies have shown that the human saliva contains certain antiviral immunoglobulins of IgA, IgG, and IgM isotypes that inhibits the growth of HIV. Though rare, transmission of the infection via human bite has been reported. The possibility of transmission from the exposure to tears, sweat and urine has been negated. Male to male contact has been the prime cause of HIV transmission followed by IDU and heterosexual routes in the United States (Figure A-3).

A.2.4 Pathogenesis

One of the main features of the HIV infection is the prolific immunodeficiency resulting because of the weakening or loss of the subset of T lymphocytes called the helper T cells. This helper T cell is characterized by the presence of the CD4 molecule on its surface and it is this site which serves as a primary target for HIV during cell attack. In order for the HIV-1 to enter in to the cell apart from the primary cellular receptor (CD4 molecule) a co-receptor is also required for efficient fusion. The destruction or depletion of this CD4+ T cells upon infection either happen either by the immune clearance of the infected cell (direct mechanism), or by immune exhaustion due aberrant cellular activation and activation-induced cell death (indirect mechanism). The virus is successful in evading the immune clearance system and is never eliminated from the human body, and it actually thrives upon the activation of the immune system. In untreated patients the HIV can persists in the system for a period of approximately 10 years before any significant clinical symptoms appear. This chronic and persistence presence of the infection is the traditional characteristic of HIV. This persistence of the virus has been attributed to its amazing ability to replicate with diversity via mutation and recombination. The progression of the virus results in further depletion of the CD4+ T cells and hence CD4+ T cells acts as a clinical measure for the progression of the disease. The concentration of these cells fall significantly in infected individuals who are either untreated or in whom the treatment is not effective in controlling the viral replication.

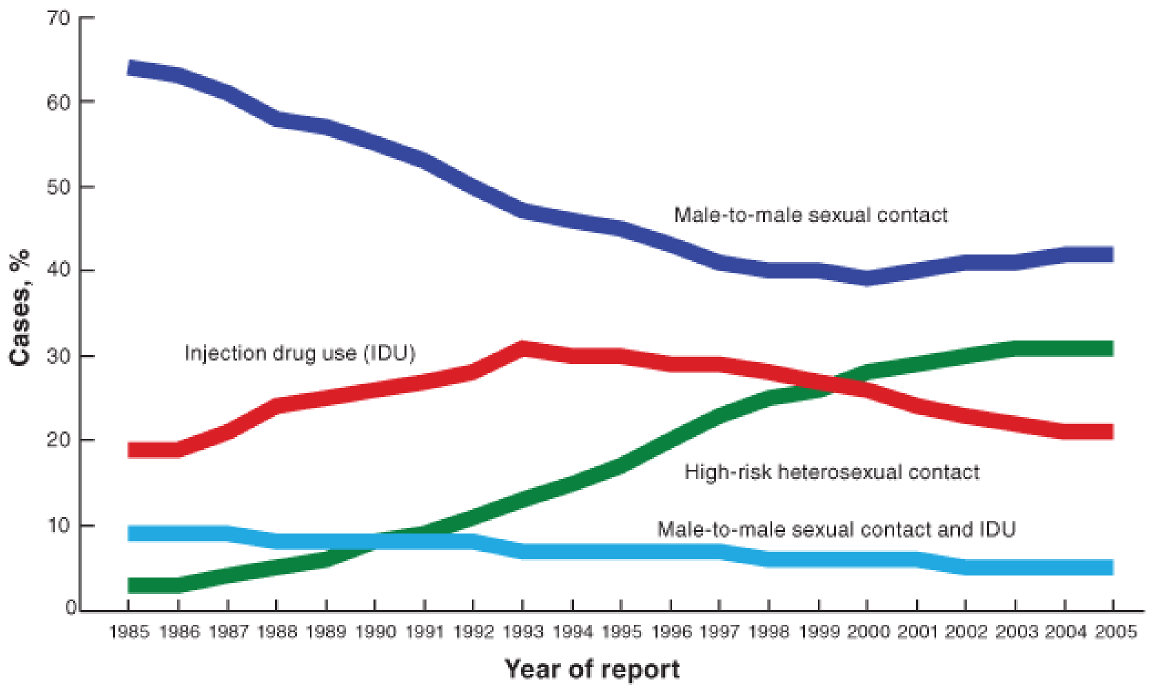


Figure A-3: AIDS cases among U.S. adults and adolescents by exposure category and year of diagnosis

(Center for Disease Control and Prevention. Epidemiology of HIV/AIDS--United States, 1981-2005. *Morb Mortal Wkly Rep.* 2006;55:589-592.)[2]

CD4+ T cells are the integral part of the body's antigen-specific immune humoral as well as cell mediated response. Continuous loss of these viral specific helper T cells has a direct impact on the control of the immune system of the other types of infections. The fall in the concentration of the CD4+ T cells below a threshold of 200/μL exposes the individual to a myriad of opportunities infections. This stage in the progression in the HIV infection is termed as Acquired Immunodeficiency Syndrome or 'AIDS' (Table A-1). Individuals with CD4+ T cells counts as low as 10/μL or even zero has been reported. This compromised immune system opens the gates for several bacterial and fungal infections. Immunological disorders such as Kaposi's sarcoma and neurological abnormalities are observed as AIDS related diseases. Respiratory infections like pneumonia, acute bronchitis, nonspecific interstitial pneumonitis, and tuberculosis are commonly seen in individuals with AIDS.

A.2.5 Diagnosis and Detection

Development of the screening and diagnostic testing took pace immediately after the establishment of HIV as a causative agent of AIDS in 1984. All blood donors were screened for the HIV antibodies sin 1985 in the United States. The early screening methods like the p24 antigen test had the ability to identify the presence of the disease after 3 months of the infection, that the time between infection and the development of the disease. But subsequent refinement of this technique shrunk the interval between infection and detection (window period) to 22 days antibody testing, later to 16 days with advanced p24 antigen testing and then finally to 12 days with the development of the nucleic acid testing (NAT).

Table A-1: 1993 Revised classification system for HIV-infected and expanded AIDS surveillance case definition for adolescents and adults

	Clinical categories		
	A	**B**	**C**
CD4+ T cell categories	**Asymptomatic, Acute (Primary) HIV or PGL***	**Symptomatic, not A or C conditions**	**AIDS-indicator conditions**
>500/uL	A1	B1	C1
200-499/uL	A2	B2	C2
<200/uL	A3	B3	C3

* PGL, progressive generalized lymphadenopathy.
(Reprinted with permission from McGraw Hill Companies, Inc®. Fauci AS, Lane CH. Human Immunodeficiency Virus Disease: AIDS and related disorder. In: Anthony S.Fauci, Dennis L.Kasper, Dan L.Longo et al, Eds. Harrison's Principles of Internal Medicine. 17th Edition. The McGraw-Hill Companies, Inc.; 2008:1137-1203.) [153]

One of the most successful screening tests used for HIV detection is the Enzyme Immunoassay (EIA), commonly known as the 'ELISA' test. The ELISA test is a combination of the antibody test and the p24 antigen test. The ELISA kit contains antigens of both HIV-1 and HIV-2 genomes from both the natural and recombinant antigen types. The ELISA test has a sensitivity of more than 99%, but the specificity of this test is highly questionable. Further confirmatory test have shown that only 10% of the individuals tested positive by ELISA test actually had the disease. Auto-antibodies and class-II antigens from the hepatic disease, recent influenza vaccination, and acute viral infection attribute to these false positive results. The Western blot test is used mostly as a confirmatory test for HIV infection. The fundamental theory behind this test is that the multiple HIV antigen of different with specific molecular weight triggers the production of specific antibodies. Each of these antibodies can be identified as discrete bands on the Western plot. This technique has high specificity which makes it a recommended confirmatory test by the U.S. Food and Drug Administration, however, its low sensitivity makes it a poor choice for screening purposes. Apart from these two commonly used tests, other test such as the DNA PCR, RNA PCR, the bDNA assay, or p24 antigen tests are available for specific information.

The serological testing guidelines for the detection of HIV infection suggest ELISA test for screening of suspected individuals. A negative test result confirms absence of the disease, unless there is a strong evidence of early infection. In case of a positive result, the same test needs to be repeated. If two consecutive repeats show negative then the initial positive result is assumed false positive or an error, and patient is considered negative for HIV infection. If the repeat test is again positive then the Western blot test is recommended as a confirmatory test. An intermediate or positive test in the Western blot confirms the infection and the individual is diagnosed as HIV positive. In case of a negative Western blot result the initial results from the ELISA test is considered as a false positive for HIV-1 and the individual is declared HIV-1 negative. At this juncture a serological test specific for HIV-2 is recommended. In case of an intermediate Western blot result a repeat test after 4-6 weeks is recommended and further testing with p24 antigen capture assay, HIV-1 RNA assay, or HIV-1 DNA PCR assay and a specific HIV-1 test is warranted. A negative result from the later tests confirms the absence of the disease in the individual. If any of later tests is positive then the individual is tentatively diagnosed for an infection which needs to be confirmed later by a positive Western blot test. One another point-of-care test available is the OraQuick Rapid HIV-1 antibody test generally to detect HIV infection in the blood, plasma, or saliva. This test has a sensitivity and specificity of about 99%. A negative result of this test confirms the absence of the infection and in case of a positive result the individual is subjected to the standard serologic testing mentioned in the guidelines (Figure A-4).

A.3 Antiretroviral Therapy

Preserving the immune function and reducing the HIV-associated morbidity and mortality are the prime objective of the antiretroviral therapy. Since plasma viral load and the CD4+ T cells are the most significant predictors for the progression of HIV

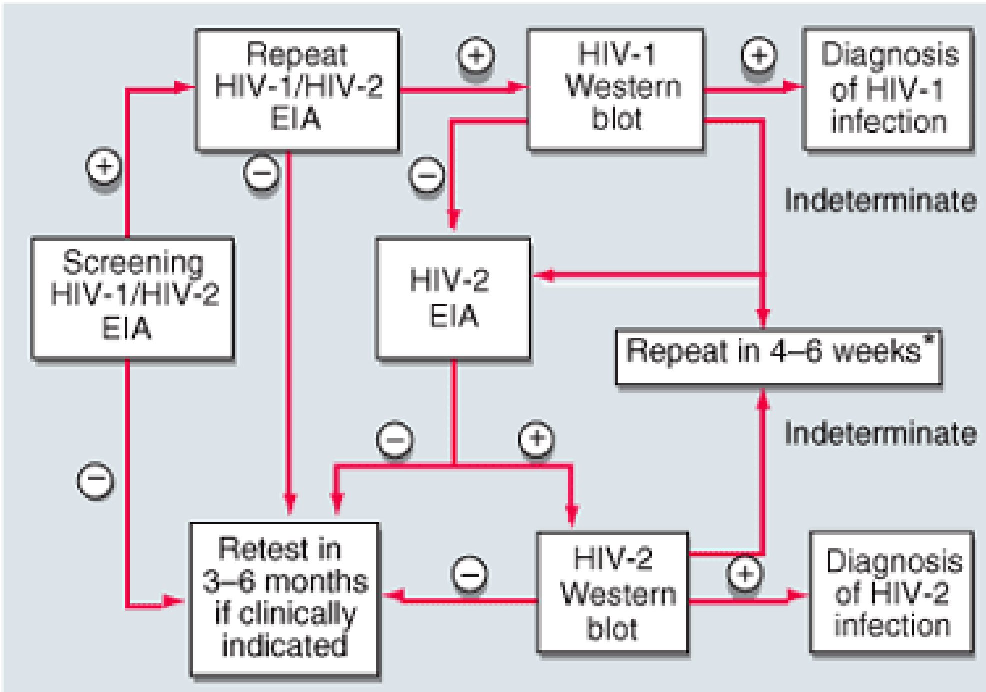


Figure A-4: Algorithm for the use of serologic tests in the diagnosis of HIV-1 or HIV-2 infection
(Reprinted with permission from McGraw Hill Companies, Inc®. Fauci AS, Lane CH. Human Immunodeficiency Virus Disease: AIDS and related disorder. In: Anthony S.Fauci, Dennis L.Kasper, Dan L.Longo et al, Eds. Harrison's Principles of Internal Medicine. 17th Edition. The McGraw-Hill Companies, Inc.; 2008:1137-1203.)[153]

infection,[5,155] hence constant monitoring of these measures is recommended along with the antiretroviral therapy to ensure the desired clinical efficacy and treatment effectiveness is achieved.[155]

According to the Guidelines for the Use of Antiretroviral Agents in HIV-1 infected Adults and Adolescents, 2008, developed by the Office of AIDS Research Advisory Council (OARAC), U.S. Department of Health and Human Services (DHHS), antiretroviral therapy needs to be initiated in patients with a history of AIDS-defining illness or with a CD4+ T cell count of less than 350 cells/mm^3.[156] The guidelines also suggests that the antiretroviral therapy should be initiated regardless of the CD4+ T cell count in pregnant women, and in patients with HIV-associated nephropathy (HIVAN) and Hepatitis B virus (HBV) coinfections (Table A-2). The combination antiretroviral therapy commonly known as the highly active antiretroviral therapy (HAART), since it use in 1995 – 1996, has been highly effective in keeping the AIDS related illness under check.[157] A recent study published in the Lancet on the patients initiated with combination antiretroviral therapy in Europe and North America showed a decrease in the mortality rates from 16.3 deaths per 1000 person years in 1996-99 to10.0 deaths per 1000 person years in 2003-05. The study also reported a decrease in the potential life lost per 1000 person years, from 366 to 189 years. And the life expectancy at age 20 years increased from 36.1 (SE 0.6) years to 49.4 (SE 0.5) years in the same cohort (Hogg, 2008).[158]

The antiretroviral drugs are classified into six different classes based on their pharmacological activity: nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs), nonnucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (FIs), fusion inhibitors, CCR5 antogonists, and integrase inhibitors.

- Nucleoside reverse transcriptase inhibitors (NRTI)
  (Zidovudine, Lamivudine, Emtricitabine, Abacavir, Didonosine, Stavudine and Tenofovir)
- Non-nucleoside reverse transcriptase inhibitors (NNRTI)
  (Efavirenz, Etravirine, Nevirapine and Delavirdine)
- Protease Inhibitors (PI)
  (Lopinavir, Ritonavir, Atazanavir, Indinavir, Nelfinavir, Saquinavir, Tipranavir and Darunavir)
- Integrase inhibitors
  (Raltagravir)
- Fusion inhibitors
  (Enfuvirtide)
- CCR5 antagonists
  (Maraviroc)

Table A-2: Indications for initiating antiretroviral therapy for the chronically HIV-1 infected patient

Clinical condition and/or CD4 count	Recommendations
➢ History of AIDS-defining illness ➢ CD4 count <200 cells/mm3 ➢ CD4 count 200-350 cells/mm3 ➢ Pregnant women ➢ Persons with HIV-associated nephropathy ➢ Persons coinfected with hepatitis B virus (HBV), when HBV treatment is indicated (Treatment with fully suppressive antiviral drugs active against both HIV and HBV is recommended).	Antiretroviral therapy should be initiated.
➢ Patients with CD4 count >350 cells/mm3 who do not meet any of the specific conditions listed above.	The optimal time to initiate therapy in asymptomatic patients with CD4 count >350 cells/mm3 is not well defined.

(Department of Health and Human Services. Guidelines for the use of antiretroviral agents in HIV-1 adults and adolescents. Accessed November 3, 2008, www.http://www.aidsinfo.nih.gov/contentfiles/adultandAdolescentGL.pdf, 2007.)[157]

A.4 Epidemiology of HIV/AIDS

A.4.1 HIV – A Global Epidemic

So far, virtually every country in the world has reported the presence of HIV among their population. According to the UNAIDS (Joint United Nations Program on HIV/AIDS) statistics the estimated population of HIV-infected cases in the world at the end of 2007 is around 33.0 million cases (30 million to 36 million).[159] Among these half of them are females and around 2.5 million cases are children less than 15 years of age. This infection has mostly affected the lower and middle income families as they account for almost 95% of the cases. Among the new cases, estimated to be around 2.5 million cases worldwide in 2007, 420,000 were children below the age of 15 years. In the year 2007, the total loss of life due to HIV or HIV- related diseases around the globe were estimated to be 2.1 million in which 330,000 were children below the age of 15 years.[159] The characteristic of the infected individuals differ between countries and is driven by the cultural and traditional norms of the country. HIV has mainly hit the poor and underdeveloped part of the globe especially the southern African countries of the sub-Saharan Africa. This part of globe consists of almost 22.5 million HIV-infected people, a two third of the world HIV population, where as their population accounts for only 10-11% of the global population.[159] In some countries in the southern African more than 15% of population between the age of 15-49 years are HIV seropositive and this proportion is more than 50% among high risk population such as commercial sex workers, patients attending STD clinics, etc. Many of these highly affected countries are expected to have a population life expectancy of less than 40 years, a significant drop from their pre-AIDS era.[159]

Recent development in the HIV prevalence in the Asian and the Central Asian countries has been alarming. Though the prevalence in some of the countries in Central Asia are less than the countries in African but the large population in these countries (like India and China) put the HIV-infected population ahead in terms of sheer numbers. At the end of 2007, the total number of HIV cases in Asia was estimated to be 4.9 million, and that in the Central Asia and Eastern Europe to be approximately 1.6 million.[159] The Russian Federation and Ukraine has been reported to have contributed to nearly 90% of the new HIV infection in 2007. This spread has been attributed to be driven by injection drug users and an increase in the heterosexual transmission.[159] In the Latin America and the Caribbean region Brazil has the largest HIV/AIDS-infected population. This region is estimated to have 1.8 million HIV/AIDS-infected cases. While North America along with Western and Central Europe account for 2.1 million of the HIV/AIDS-infected population (Figure A-5).[159]

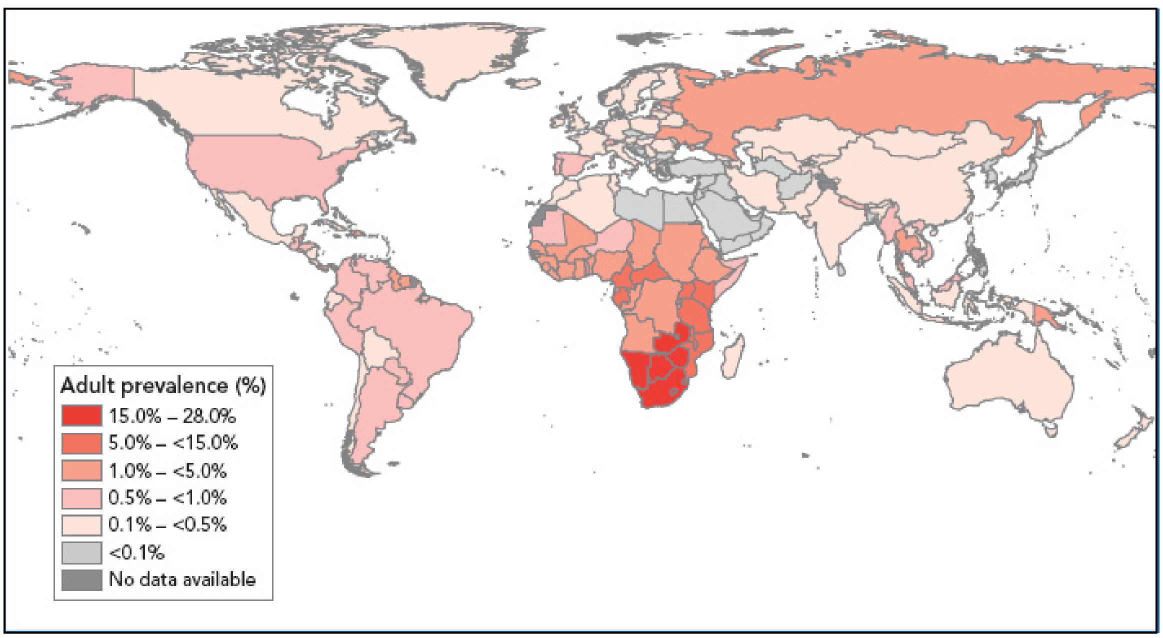


Figure A-5: Global view of HIV infection
(Reprinted from the United Nations AIDS Program (UNAIDS). Report on Global AIDS Epidemic. UNAIDS/08.27E / JC1511E. 2008. Accessed April 3, 2009, www.unaids.org.)[160]

A.4.2 HIV/AIDS in United States

Since 1981 the number of AIDS cases in the United States has increased rapidly and reached its peak in 1992. Around 78,000 cases of HIV were diagnosed in 1992.[2] However, this rapid growth stabilized in 1998, mostly because of tremendous public awareness and safety drives coupled with the development of HAART guidelines (Figure A-6). Trends show a drop of 47% in the number for cases from 1992 to 1998. Although males accounted for the majority of the cases a rise in the proportion of females has been observed in recent trend analysis. Statistics confirm a rise from 15% (1981-1995) to 27% (2001-2004) in the females among the all AIDS cases.[2] In the mean time a decrease in the proportion of cases aged <13 years has been observed between the periods 1981-1985 to 2001-2004.

Annually, nearly 56,000 new cases of HIV infection are identified in the United States. The MMWR (2008) report estimates put the current population of 'People Living with HIV/AIDS (PLWHA) in the United States to be 1.1 million. This number includes all adults and adolescents either diagnosed or undiagnosed at the end of 2006.[39] Compared to the 994,000 HIV cases estimated in 2003, there has been an 11.3% increase in the PLWHA population in the United States. Among them 46.1% (1,715.1 per 100,000 population) were black, 34.6% (224.3 per 100,000) were white, 17.5% (585.3 per 100,000) were Hispanic, 1.4% (129.6 per 100,000) were Asian/Pacific Islander, and 0.4% (231.4 per 100,000) were American Indian/Alaska Native. Gender wise, males made up the largest portion accounting 74.8% of prevalent HIV cases (685.7 per 100,000). Among males 64.3% of them reported to have male-to-male sexual contact, and thus accounting for 48.1% of the total HIV-infected population. Infection resulting from heterosexual contact accounted for 27.6% of the prevalent cases (1.6% among men and 72.4% of cases among women), 18.5% of the cases was attributed to injection drug use (IDU) and the balance 5% accounted to men who reported both male-to-male sexual contact and IDU or whose transmission category was classified as other (0.8%; including hemophilia, blood transfusion, perinatal exposure, and risk factors nor reported or not identified).[39]

The MMWR 2006 report also reported that almost 24%-27% of the HIV population is unaware of their HIV infection and more than half of the individuals had their first diagnosed HIV-positive within 12 months of AIDS diagnosis (MMWR, 2003).[39]

In the State of Tennessee, as of 2005 some 11,867 cases of HIV/AIDS were identified and out them 6,133 cases are currently living with AIDS.[161] Eighty one percent of the HIV/AIDS population in the State of Tennessee are females and 51% of the reported cases are Black, non-Hispanics. Around 4,449 cases have been reported in the Shelby County so far. The number of HIV cases per 100,000 population is Memphis is about 313 as of 2007, and 89% of these cases are Black, non-Hispanics.[162]

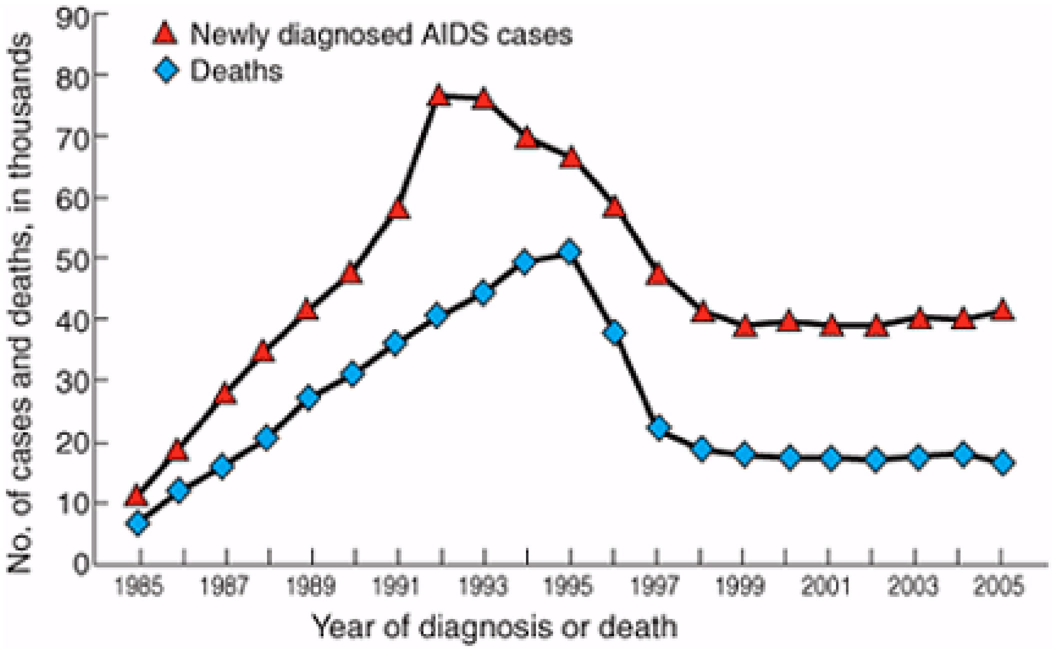
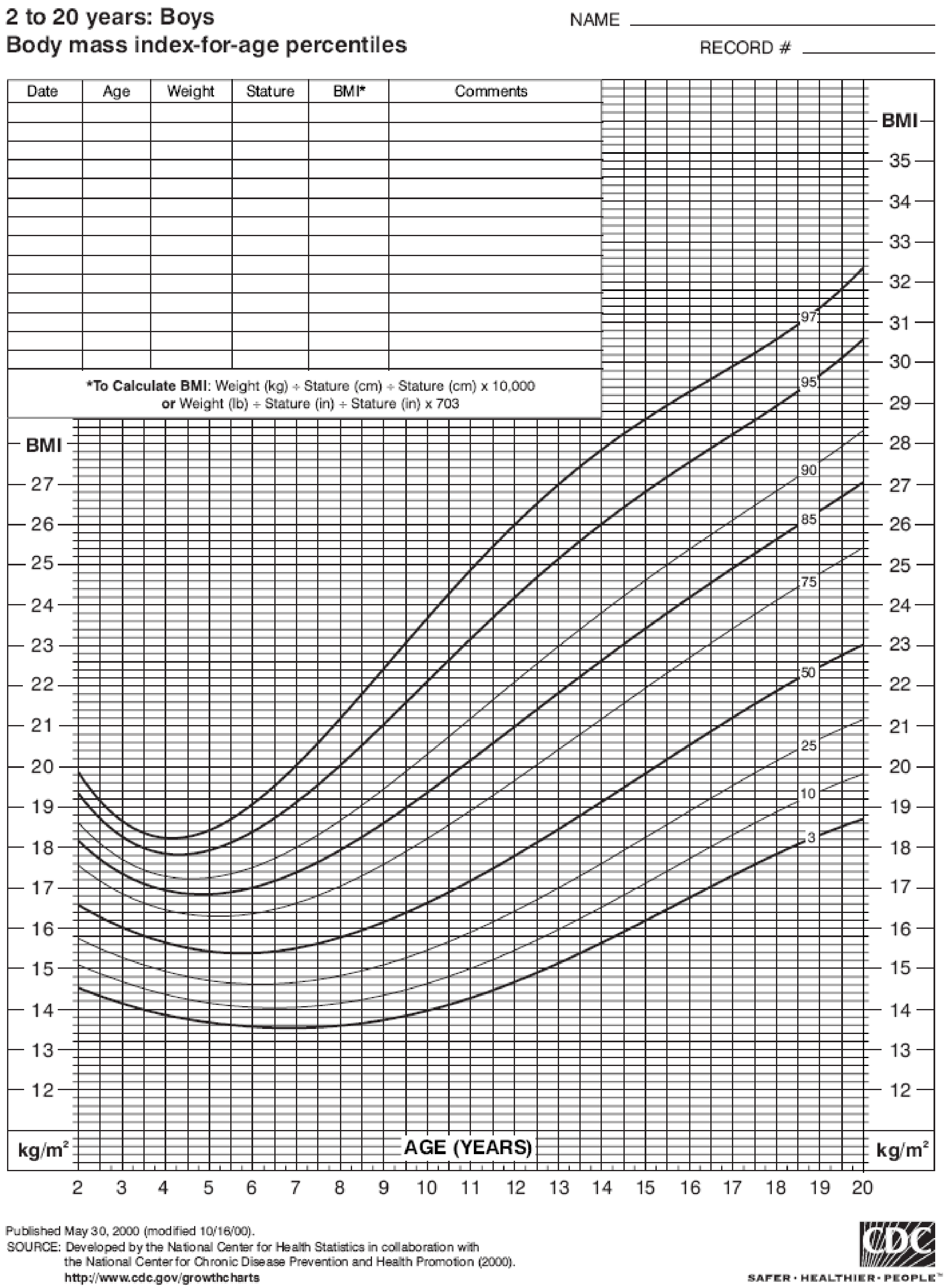


Figure A-6: Estimated number of AIDS cases and AIDS deaths, United States, 1985-2005

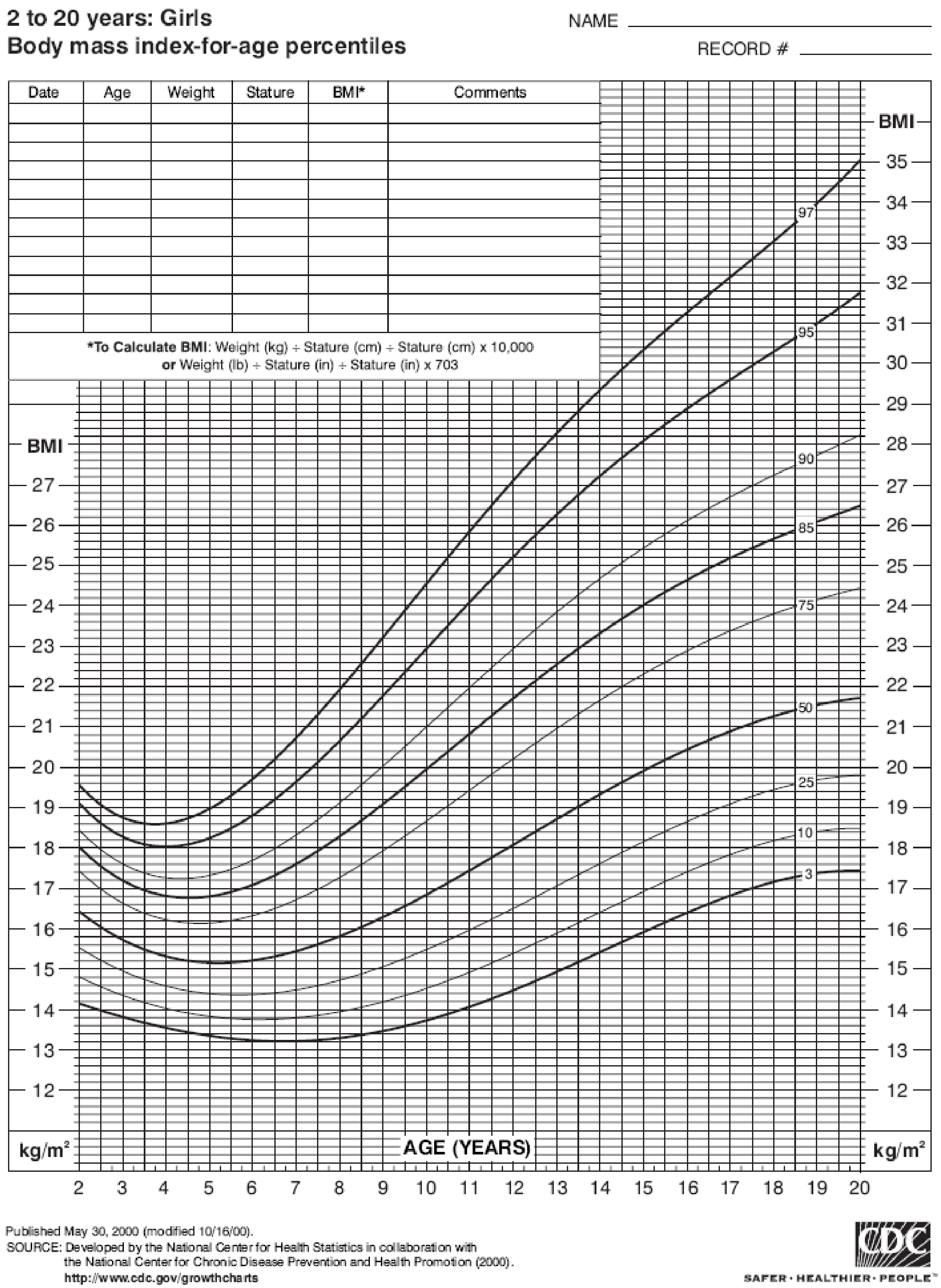
(Center for Disease Control and Prevention. Epidemiology of HIV/AIDS--United States, 1981-2005. Morb Mortal Wkly Rep. 2006;55:589-592.)[2]

APPENDIX B: INSTRUMENTS USED IN THE STUDY

B.1 CDC BMI Chart for Boys



B.2 CDC BMI Chart for Girls



B.3 IRB-Approved Questionnaire for Parent

Page 1

QUESTIONNAIRE (PARENT)

Subject Identification No.: ☐☐☐☐☐ ☐ Date of visit: (mm / dd / yy)

Study site: ------------------------------- -------------------------

PARENT'S DEMOGRAPHIC INFORMATION

1) Date of Birth ☐ ☐ ☐ (mm/dd/yy) Age(yrs) ☐ Sex: M ☐ F ☐

2) Marital Status: ☐ Single ☐ Married ☐ Divorced

3) Race: ☐ White ☐ Black ☐ Asian
☐ Native Hawaiian / Pacific Islander ☐ American Indian / Alaska Native
☐ Others

4) Ethnicity: ☐ Hispanic ☐ Non Hispanic

5) Education status:
Number of years of education ☐

Highest degree attained:

☐ No Degree ☐ GED ☐ High School Diploma ☐ Bachelor's Degree

☐ Master's Degree ☐ Other (pl specify) ---------------

6) Number of children staying with you in your home: ☐

7) Does any of your children (child) have HIV? ☐ Yes ☐ NO

8) Family income:

Please indicate the category which best represents your total annual family income

☐ 1 – 2,500.
☐ 2,501 – 5,000
☐ 5,001 – 10,000
☐ 10,001 – 20,000
☐ 20,001 – 30,000
☐ 30,001 – 40,000
☐ 40,001 – 50,000
☐ 50,001 – 75,000
☐ 75,001 – 100,000
☐ 100,001 OR MORE

The University of Tennessee Health Science Center IRB NUMBER: IRB# 08-00188-XM
IRB APPROVAL DATE: 12/02/2008

9) Please select from the below the type of your health insurance.

- ☐ Ryan White
- ☐ Private health insurance
- ☐ Medicaid
- ☐ Medi-Gap
- ☐ Medicare/Tenncare
- ☐ SCHIP (Children Health Insurance Program) / Cover-kids
- ☐ Military health care (TRICARE/VA/CHAMP-VA)
- ☐ Indian Health Services
- ☐ State-sponsored health plan
- ☐ Other governmental program

10) Do you have prescription drug coverage as a part of your health insurance plan?

- ☐ Yes
- ☐ No

11) Do you have dental coverage as a part of your health insurance plan?

- ☐ Yes
- ☐ No

12) Do you have vision (eye) coverage as a part of your health insurance plan?

- ☐ Yes
- ☐ No

PARENT'S HEALTH INFORMATION

13) What year did your doctor first tell you that you had HIV? ☐

14) Did you have your CD4 count measured in the past 6 months: Yes ☐ No ☐

- Please enter your latest CD4 count ☐

B.4 IRB-Approved Questionnaire for Child

QUESTIONNAIRE (CHILD)

Parent Identification No.: ☐☐☐☐☐☐ Date of visit: ☐ (mm / dd / yy)

Child Identification No.: ☐☐☐☐☐☐

Study site: ------------------------------- -------------------------

CHILD'S DEMOGRAPHIC INFORMATION

Date of Birth ☐ ☐ ☐ (mm/dd/yy) Age(yrs) ☐ Sex: M ☐ F ☐

Education status:
Number of years of education ☐

Height of your child: ☐ feet ☐ inches

Weight of your child (in lbs.) ☐

PARENT'S PERCEPTION OF THEIR CHILD'S HEALTH

1) The following are statements about your Child's general health status.
How true or false is each of these statements for your child?

1 = DEFINITELY TRUE 2 = MOSTLY TRUE 3 = DON'T KNOW 4 = MOSTLY FALSE 5 = DEFINITELY FALSE

a. My child seems to be less healthy than other children that I know. ☐

b. My child has never been seriously ill. ☐

c. When there is something going around, my child usually catches it. ☐

d. I expect my child will have a very healthy life. ☐

e. I worry more about my child's health more than other people worry about their children's health. ☐

CHILD'S IMMUNIZATION INFORMATION

2) Please check the vaccinations that your child has had

2a)	Polio	Yes ☐	NO ☐	Don't know ☐
2b)	DTP/DTaP/DT	Yes ☐	NO ☐	Don't know ☐
2c)	MMR	Yes ☐	NO ☐	Don't know ☐
2d)	Hepatitis B	Yes ☐	NO ☐	Don't know ☐
2e)	Varicella	Yes ☐	NO ☐	Don't know ☐

CHILD'S HEALTHCARE ACCESS INFORMATION

3) Is there a particular doctor's office, clinic, health center, or other place that your child usually goes if he/she is sick or you need advice about your child's health?

- ☐ YES
- ☐ NO
- ☐ MORE THAN ONE PLACE

4) If NO to previous question then, what are the **main** reasons your child does not have a usual source of health care? Check all that apply.

- ☐ SELDOM OR NEVER GETS SICK
- ☐ RECENTLY MOVED INTO AREA
- ☐ DON'T KNOW WHERE TO GO FOR CARE
- ☐ USUAL SOURCE OF MEDICAL CARE IN THIS AREA IS NO LONGER AVAILABLE
- ☐ CAN'T FIND A PROVIDER WHO SPEAKS YOUR LANGUAGE
- ☐ LIKES TO GO TO DIFFERENT PLACES FOR DIFFERENT HEALTH NEEDS
- ☐ JUST CHANGED INSURANCE PLANS
- ☐ DON'T USE DOCTORS/TREAT MYSELF
- ☐ COST OF MEDICAL CARE
- ☐ OTHER REASON

5) How does your child usually get to their healthcare provider?

- ☐ DRIVE
- ☐ IS DRIVEN
- ☐ TAXI, BUS, TRAIN, OTHER
- ☐ PUBLIC TRANSPORTATION
- ☐ WALKS

6) How long does it take him/her to get to their healthcare provider?

- ☐ LESS THAN 15 MINUTES
- ☐ 15 TO 30 MINUTES
- ☐ 31 MINUTES TO 60 MINUTES (1 HOUR)
- ☐ 61 MINUTES TO 90 MINUTES
- ☐ 91 MINUTES TO 120 MINUTES (2 HOURS)
- ☐ MORE THAN 120 MINUTES (2 HOURS)

7) How difficult is it for your child to get to their provider? Would you say it is….

- ☐ very difficult,
- ☐ somewhat difficult,
- ☐ not too difficult or
- ☐ not at all difficult?

8) Is their provider a nurse, nurse practitioner, physician's assistant, midwife, or some other kind of person?

- ☐ MEDICAL DOCTOR
- ☐ NURSE
- ☐ NURSE PRACTITIONER
- ☐ PHYSICIAN'S ASSISTANT
- ☐ MIDWIFE
- ☐ OTHER

8) Does your child have health insurance?

- ☐ Yes
- ☐ NO

If your answer to Question # 8 is no, then please go to Question # 13

9) Please select from below the type of your child's health insurance.

- ☐ Ryan White
- ☐ Private health insurance
- ☐ Medicaid
- ☐ Medi-Gap
- ☐ Medicare/Tenncare
- ☐ SCHIP (Children Health Insurance Program) / Cover-kids
- ☐ Military health care (TRICARE/VA/CHAMP-VA)
- ☐ Indian Health Services
- ☐ State-sponsored health plan
- ☐ Other governmental program

10) Does your child's insurance have prescription drug coverage as a part of his/her insurance plan?

- ☐ Yes
- ☐ No

11) Does your child's insurance have dental coverage as a part of his/her insurance plan?

- ☐ Yes
- ☐ No

The University of Tennessee Health Science Center IRB NUMBER: IRB# 08-00188-XM
IRB APPROVAL DATE: 12/02/2008

12) Does your child's insurance have vision (eye) coverage as a part of his/her insurance plan?

- ☐ Yes
- ☐ No

CHILD'S HEALTHCARE UTILIZATION INFORMATION

13) Does your child currently use **medicine prescribed by a doctor**, other than vitamins?

- ☐ YES
- ☐ NO

14) Is this because of **any** medical, behavioral or other health condition?

- ☐ YES
- ☐ NO

15) In the past 12 months how many times has your child made a visit to a doctor for any medical reasons?

☐

16) In the past 12 months how many times has your child visited a hospital and been admitted for medical reasons?

☐

17) In the past 12 months how many times has your child made a visit to the emergency department of the hospital for medical reasons?

☐

CHILD'S HEALTH OUCOMES INFORMATION

18) In the past 12 months for any of the medical reasons have your child missed school?

- ☐ Yes
- ☐ No
- ☐ Does not go to school

19) In the past 12 months, how many days did your child miss a half day or more of school / daycare because of a physical illness or injury, or a mental or emotional problem?

☐

THE UNIVERSITY of TENNESSEE HEALTH SCIENCE CENTER IRB NUMBER: IRB# 08-00188-XM
IRB APPROVAL DATE: 12/02/2008

APPENDIX C: IRB-APPROVED DOCUMENTS

C.1 University of Tennessee Health Science Center IRB Approval-1

THE UNIVERSITY OF TENNESSEE
Health Science Center

Institutional Review Board
910 Madison Avenue, Suite 600
Memphis, TN 38163
Tel: (901) 448-4824

December 02, 2008

Arijit Ganguli
College of Medicine
Center for Health Policy
Johnson Building
Suite 205
UTHSC

Re: IRB# 08-00188-XM
Study Title: Understanding variations in the healthcare utilization, healthcare access, health investment, and health outcomes of uninfected children of HIV seropositive and seronegative parent(s)

Dear Mr. Ganguli,

The Administrative Section of the UTHSC Institutional Review Board (IRB) reviewed your application for the above referenced project.

The Administrative Section of the IRB determined your application to be consistent with the guidelines for **exempt** review under 45CFR46.101(b)(2). In accord with 45CFR46.116 (d), informed consent may be altered with a cover statement used in lieu of an informed consent interview. The requirement to secure a signed consent form is waived under 45CFR46.117(c)(2). Willingness of the subject to participate will constitute adequate documentation of consent.

Therefore your application has been determined to comply with proper consideration for the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects. This letter constitutes full approval of your application, questionnaire(s); script and consent cover statement stamped approved by the IRB on December 2, 2008 for the above referenced study.

In the event that volunteers are to be recruited using solicitation materials, such as brochures, posters, web-based advertisements, etc., these materials must receive prior approval of the IRB.

Any alterations (revisions) in the protocol, questionnaire(s); script and consent cover statement must be promptly submitted to and approved by the UTHSC Institutional Review Board prior to implementation of these revisions. You have individual responsibility for reporting to the Board in the event of unanticipated or serious adverse events and subject deaths.

Sincerely,

Signature applied by Terrence F Ackerman on 12/02/2008 02:02:12 PM CST

Signature applied by Donna L Stallings on 12/02/2008 02:03:15 PM CST

Terrence F. Ackerman, Ph.D.
Chairman
UTHSC IRB

Donna Stallings, CIM
IRB Administrator
UTHSC IRB

C.2 University of Tennessee Health Science Center IRB Approval-2

THE UNIVERSITY OF TENNESSEE
Health Science Center

Institutional Review Board
910 Madison Avenue, Suite 600
Memphis, TN 38163
Tel: (901) 448-4824

August 20, 2009

Arijit Ganguli
UTHSC - COM - Center for Health Policy
RM 205 Johnson Building
847 Monroe Avenue
Memphis, TN 38163--0000

Re: 08-00188-XM
Study Title: Impact of Parent's HIV Status on their Uninfected Child - A Comparative Analysis of the Child's Healthcare Utilization, Access and Health Outcomes.

Dear Dr. Ganguli:

The Administrative Section of the UTHSC Institutional Review Board (IRB) reviewed your application for **revision** of your previously approved project, referenced above.

The Administrative Section of the IRB determined your application to be consistent with the guidelines for **exempt** status under 45CFR46.101(b)(2). Therefore, the attached revisions to your project were approved in this regard as complying with proper consideration of the rights and welfare of human subjects, the risk involved, and the potential benefits of the study.

The revisions to this study may not be instituted until you receive approval from the institution(s) where the research is being conducted.

In the event that volunteers, either subjects or patients, are to be recruited by means other than usual and standard patient care practices, the Board must approve of any such solicitation materials (i.e., advertising copies or posters, etc.)

Any alterations (revisions) in the research project must be submitted to and approved by the UTHSC Institutional Review Board prior to implementation to these revisions.

Sincerely,

Signature applied by Terrence F Ackerman on 08/20/2009 02:35:42 PM CDT

Signature applied by Bonnie L Binkley on 08/20/2009 02:36:36 PM CDT

Bonnie Binkley, MA, CIM, CIP
IRB Analyst
UTHSC IRB

Terrence F. Ackerman, Ph.D.
Chairman
UTHSC IRB

Attachment: Revisions

1. The study application's title was changed from "Understanding variations in the healthcare utilization, healthcare access, health investment, and health outcomes of uninfected children of HIV seropositive and seronegative parent(s)" to "Impact of Parent's HIV Status on their Uninfected Child - A Comparative Analysis of the Child's Healthcare Utilization, Access and Health Outcomes". The revised study application is version 1.2.

C.3 IRB-Approved Script Used for Recruiting Study Participants

SCRIPT

STEP I

"Hello, my name is Arijit Ganguli. I am a graduate student at the University of Tennessee and I am doing a research study on children staying with their HIV infected family. Can I talk to you for a few minutes?"
(If the answer is 'YES' then continue further, and if 'NO' then say "Thank you for your time.")

STEP II

"I have been informed that you are a HIV person by (NAME), may I know if you have children (child) who are (is) not HIV infected and currently staying with you".
(If the answer is 'YES' then continue further, and if 'NO' then say "Thank you for your time.")

STEP III

"The purpose of my study is to understand the healthcare utilization, healthcare access and health outcomes of uninfected children residing in HIV affected homes. Based on the findings, this study plans to recommend health policy changes to address your child's healthcare needs.

Approximately 100 subjects will be participating in this study at 3 centers in Memphis and they are - Adult Special Care clinic, Friends for Life and Hope House Daycare. If you agree to participate, you will be required to answer a few questions related to you and your child's healthcare utilization, access to healthcare services and his/her health outcomes. The complete survey should require no longer than 15-20 minutes of your time.

The interview does not pose any foreseeable risks or discomforts to you. Your participation in this study is totally voluntary. You have the right to withdraw from this study at any time with no penalty or loss of rights to which you are entitled. Your answering the questions will be considered as your permission to use your responses to the survey questions in the study.

For the confidentiality of your interview responses, your name or your child's name will not be asked during the interview. Your record will be labeled with a code number. Also during the interview no questions regarding your place of residence or any kind of contact details will be asked. All the completed surveys will be kept in a lock & key cabinet accessed only by authorized personal in this study."

STEP IV

Provide one copy of the questionnaire to the study participant and use another copy to READ the survey questions aloud to the participant. Document the answers given by the participant for each question in your copy.

STEP V

Upon completion of the survey say "Thank you for your time and the valuable information you have provided for this study. This is my business card, please feel free to call me if you any questions regarding this study".

IRB Approval # Subject Initials _____
Reference Date: Revised on: 10/22/08

THE UNIVERSITY of TENNESSEE UT HEALTH SCIENCE CENTER IRB NUMBER: IRB# 08-00188-XM
IRB APPROVAL DATE: 12/2/2008

C.4 MED IRB Approval-1

Regional Medical Center at Memphis

December 19, 2008

THE MED

Arijit Ganguli
Center for Health Policy
UTHSC - College of Pharmacy
Johnson Building, Suite 205
Memphis, TN 38163

Dear Mr. Ganguli:

The project proposal entitled **"Understanding Variations in the Healthcare Utilization, Healthcare Access, Health Investment, and Health Outcomes of Uninfected Children of HIV Seropositive and Seronegative Parent(s)" (IRB # 08-00188-XM)** has been reviewed by this office. The goals of the project appear to be consistent with the commitment of the Regional Medical Center to the advancement of medical science and healthcare, and I am pleased to inform you of its approval, with several restrictions:

- Current space constraints and existing room turnover issues mandate that if patient flow is interrupted as a result of this survey, Dr. John Norwood can determine that this site must opt out of participation in this project.
- If the survey becomes problematic for patients, this, too, will be cause for the clinic to opt out of continued participation.

I appreciate your understanding of these restrictions, because the care of and wellbeing of our patients is our primary responsibility.

For your convenience, the following list will serve as a reminder of some of your responsibilities as the principal investigator at this site. All members of your research team must be aware of these requirements to ensure compliance with the MED's policies for conducting research (items applicable to this study have been listed). Please refer to "Research Policies" in the MED's Administrative Manual for a complete listing. Please note that none of these are new requirements; if you have any questions, please call the Office of Medical Research at 545-7453.

1. Any revisions in the protocol must be forwarded to the Office of Medical Research.
2. Upon completion of the study, the Research Office must be informed of the end date.

877 Jefferson Avenue Memphis, TN 38103 901.545.7100

I commend you for your research activity and look forward to hearing from yo regarding the outcome of this study. If our office may be of help to you in connection with this project or with future endeavors, please let us know.

Sincerely,

Jack D. McCue, M.D.
Chief Medical Officer

CC Maria van Werkhooven, Director,
Office of Medical Research

C.5 MED IRB Approval-2

Regional Medical Center at Memphis

August 20, 2009

Arijit Ganguli
Center for Health Policy
UTHSC - College of Pharmacy
Johnson Building, Suite 205
Memphis, TN 38163

THE MED

Dear Mr. Ganguli:

We have been advised of the UTHSC IRB's approval of your application for a revision, changing the title of your study (IRB # 08-00188-XM) from "*Understanding Variations in the Healthcare Utilization, Healthcare Access, Health Investment, and Health Outcomes of Uninfected Children of HIV Seropositive and Seronegative Parent(s)*" to "*Impact of Parent's HIV Status on their Uninfected Child - A Comparative Analysis of the Child's Healthcare Utilization, Access and Health Outcomes*".

This change has been reviewed by this office, and The Regional Medical Center at Memphis hereby authorizes you to proceed with the study (IRB # 08-00188-XM) at The MED with the IRB-approved revision.

If our office may be of help to you in connection with this project or with future endeavors, please let us know.

Sincerely,

Maria van Werkhooven, BVM, MHA, FACHE
Director, Office of Medical Research

877 Jefferson Avenue Memphis, TN 38103 901.545.7100

C.6 Study Site Approval from Friends for Life

FRIENDS FOR Life

...helping persons affected by HIV/AIDS live well...

www.friendsforlifecorp.org
Ph. 901.272.0855
F. 901.272.7458
43 North Cleveland
Memphis, TN 38104

Mailing Address:
PO Box 41853
Memphis, TN 38174-1853

September 1, 2008

Arijit Ganguli
Center for Health Policy
UTHSC – College of Pharmacy
Johnson Building, Suite 205
Memphis, TN 38163

Dear Mr. Ganguli:

The project proposal entitled **"Impact of Parent's HIV Status on their Child – A Comparative Analysis of the Child's Healthcare Utilization, Access, and Health Outcomes"** has been reviewed by this office. The goals of the project appear to be consistent with the commitment of Friends For Life to the advancement of medical science and healthcare, and I am pleased to inform you of its approval.

I commend you for your research activity and if I can be of any assistance to you, please feel free to call me at 901-272-0855, ext.240.

Sincerely,

Kim Daugherty, LMSW
Executive Director

C.7 Study Site Approval from Hope House Day Care

HOPE
HOUSE

P.O. Box 41437
Memphis, TN 38174-1437
Telephone 901.272.2702
Fax 901.722.9520
www.hopehousedaycare.org

August 19, 2008

Arijit Ganguli
Center for Health Policy
UTHSC – College of Pharmacy
Johnson Building, Suite 205
Memphis, TN 381163

Dear Mr. Ganguli:

The project proposal entitled **"Impact of Parent's HIV status on their Child – A comparative Analysis of their Child's Healthcare Utilization, Access and Health Outcomes"** was approved by our agency and will be administered to the clients we serve. I look forward to working with you on this project and trust that your research activity will go as planned. I am anticipating hearing the results of the research findings.

Sincerely,

Maria Randall, MSSW

Maria Randall, MSSW
Director of Social Services

Hope House is supported through voluntary contributions. Founded by the Junior League of Memphis.

APPENDIX D: LETTERS OF PERMISSION

D.1 Permission to Reprint the Andersen Healthcare Utilization Behavioral Model in the Study

Reply | Reply to all | Forward | Help

You forwarded this message on 6/24/2009 1:39 PM.

From: Ganguli, Arijit   Sent: Tue 6/23/2009 3:21 PM
To: randerse@ucla.edu
Cc:
Subject: Permission to reprint the Behavioral Model
Attachments:

Dear Dr. Andersen,

As an introduction, my name is Arijit Ganguli and I am a Graduate PhD student in Health Outcomes & Policy Research program in the University of Tennessee, Memphis. My dissertation topic deals with analyzing the impact of parent's HIV status on the healthcare utilization, access and health outcomes of their children.

The main reason of this communication is for the reason that I have used the Behavioral Model for Health Services Use, developed by you, as one of the concepts to define my study design. As a part of my literature review I have described the Behavioral Model in detail, however, for a better understanding I would like to provide the schematic figure of the model. Hence I would like to have your permission to reprint the 'Emerging Model' from the article "Revisiting the Behavioral Model and Access to Medical Care: Does it Mater? published in the Journal of Health and Social Behavior, Volume 36,No.1(Mar., 1995) pp 1-10.

I will greatly obliged if you can permit me to reprint the model.

Awaiting your response and thanking you in anticipation.

Best regards,

Arijit Ganguli
Graduate Ph.D. Student
Health Outcomes & Policy Research,
University of Tennessee Health Science Center
Phone: 901-448-1152
Email: aganguli@utmem.edu

D.2 Permission to Reprint Structure of HIV-1 Virion Particle

From: Ganguli, Arijit
Sent: Wed 6/24/2009 2:05 PM
To: snallo@ihv.umaryland.edu
Cc:
Subject: Permission to reprint
Attachments:

Dear Dr. Gallo,

As an introduction, my name is Arijit Ganguli and I am a Graduate PhD student in Health Outcomes & Policy Research program in the University of Tennessee, Memphis. My dissertation topic deals with analyzing the impact of parent's HIV status on the healthcare utilization, access and health outcomes of their uninfected children.

The main reason of this communication is that as a part of my dissertation literature review I have described the morphology and replication of the HIV virus. In order to compliment my text I would also like to provide a visual that illustrates the text. Hence I will like to have your permission to reprint the which has been printed as Figure 182-2B in the Chapter 182 of Section 14 (Part 7): Human Immunodefiency Virus Disease: AIDS and related disorder, Harrison's Principles of Internal Medicine, 17th Edition (2008). The same was taken from your published article - Gallo, R.C. "The AIDS Virus." *Scientific American* 256:46-56, 1987.

I will greatly obliged if you can permit me to reprint the above mentioned figures and table.

Awaiting your response and thanking you in anticipation.

Best regards,

Arijit Ganguli
Graduate Ph.D. Student
Health Outcomes & Policy Research,
University of Tennessee Health Science Center
Phone: 901-448-1152
Email: aganguli@utmem.edu

D.3 Permission to Reprint Figures of Replication of Life Cycle of HIV, Algorithm for the Serological Test in Diagnosis of HIV Infection and 1993 Revised Classification System of HIV Infection

Dated: June 25th 2009

The University of Tennessee Health Science Center
847 Monroe Avenue, Room 205,
Memphis, TN – 38104.
Email: aganguli@utmem.edu
Tel: 001-901-4481152

Kind attention:

The McGraw-Hill Companies
Permissions Department
Two Penn Plaza, 9th Floor
New York, NY 10121-2298

Subject: Permission to reprint book excerpts

As an introduction, my name is Arijit Ganguli and I am a Graduate PhD student in Health Outcomes & Policy Research program in the University of Tennessee, Memphis. My dissertation topic deals with analyzing the impact of parent's HIV status on the healthcare utilization, access and health outcomes of their children.

As a part of my dissertation, I have a detailed description on morphology and replication of the HIV virus. In order to compliment my text I would also like to provide some visual figures/diagrams that illustrate the text. Therefore, I will like to have your permission to reprint the figures/tables from the Chapter 182 of Section 14 (Part 7): Human Immunodeficiency Virus Disease: AIDS and related disorder, Harrison's Principles of Internal Medicine, 17th Edition (2008). This chapter is authored by Antony S. Fauci and H. Clifford Lane. The material was accessed from an online version of the book available to the students of University of Tennessee Health Science Center on http://online.statref.com website. The figures/tables for which the permission is requested are as follows:

1. Figure 182-2B: Structure of HIV-1, including the gp120 outer membrane, gp41 transmembrane components of the envelope, genomic RNA, enzyme reverse transcriptase, p18(17) inner membrane (matrix), and p24 core protein (capsid) (copyright by George V. Kelvin). *(Adapted from RC Gallo: Sci Am 256:46, 1987.)*.
2. Figure 182-3: The replication cycle of HIV. See text for description. (*Adapted from Fauci, 1996*.)
3. Figure 182-27: Algorithm for the use of serologic tests in the diagnosis of HIV-1 or HIV-2 infection.
4. Table 182-1: 1993 Revised Classification system for HIV infection and expanded AIDS surveillance case definition for adolescents and adults. *Source:* MMWR 42(No. RR-17), December 18, 1992.

The dissertation is still under process of completion and the author (Arijit Ganguli) aims to complete the writing process by the December, 2009. The format of the new work will be in MS Word and in Adobe PDF formats and the work will be in English language. The dissertation upon completion will be a part of the University of Tennessee Health Science Center's library. The dissertation is purely for education purpose and in partial fulfillment of my Degree of Philosophy (Ph.D.). Please find the excerpts (5 pages) which are a part of my dissertation enclosed along with this letter for your reference and further approval.

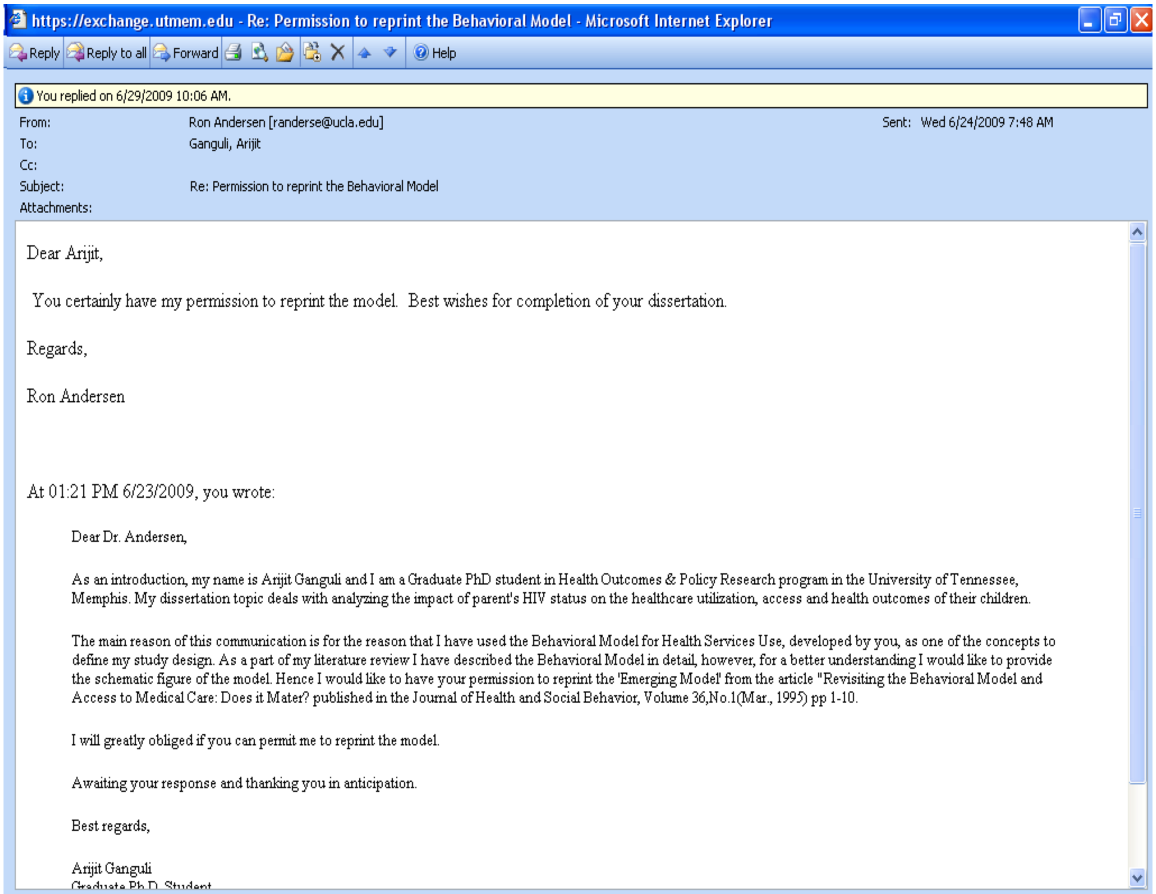
I will be greatly obliged if you can permit me to reprint the above mentioned figures and table.

Awaiting your response and thanking you in anticipation.

Best regards,

Arijit Ganguli
Graduate Ph.D. Student
Health Outcomes & Policy Research,
University of Tennessee Health Science Center

D.4 Letter of Approval to Use Andersen Healthcare Utilization Behavioral Model



https://exchange.utmem.edu - Re: Permission to reprint the Behavioral Model - Microsoft Internet Explorer

Reply | Reply to all | Forward | Help

You replied on 6/29/2009 10:06 AM.

From: Ron Andersen [randerse@ucla.edu] Sent: Wed 6/24/2009 7:48 AM
To: Ganguli, Arijit
Cc:
Subject: Re: Permission to reprint the Behavioral Model
Attachments:

Dear Arijit,

You certainly have my permission to reprint the model. Best wishes for completion of your dissertation.

Regards,

Ron Andersen

At 01:21 PM 6/23/2009, you wrote:

Dear Dr. Andersen,

As an introduction, my name is Arijit Ganguli and I am a Graduate PhD student in Health Outcomes & Policy Research program in the University of Tennessee, Memphis. My dissertation topic deals with analyzing the impact of parent's HIV status on the healthcare utilization, access and health outcomes of their children.

The main reason of this communication is for the reason that I have used the Behavioral Model for Health Services Use, developed by you, as one of the concepts to define my study design. As a part of my literature review I have described the Behavioral Model in detail, however, for a better understanding I would like to provide the schematic figure of the model. Hence I would like to have your permission to reprint the 'Emerging Model' from the article "Revisiting the Behavioral Model and Access to Medical Care: Does it Mater? published in the Journal of Health and Social Behavior, Volume 36,No.1(Mar., 1995) pp 1-10.

I will greatly obliged if you can permit me to reprint the model.

Awaiting your response and thanking you in anticipation.

Best regards,

Arijit Ganguli
Graduate Ph.D. Student

D.5 Approval to Reprint the Structure of HIV-1 Virion Particle

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Dr. Gallo has asked that I inform you that you have his permission but you should be sure to also get permission from Scientific American.

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Suna Nallo

Suna Nallo
Assistant to Robert C. Gallo, MD
Institute of Human Virology
University of Maryland
School of Medicine
725 W. Lombard Street
Suite S307
Baltimore, MD 21201
phone: 410-706-8614
fax: 410-706-1952
email: snallo@ihv.umaryland.edu
www.ihv.org

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Dear Dr. Gallo,

As an introduction, my name is Arijit Ganguli and I am a Graduate PhD student in Health Outcomes & Policy Research program in the University of Tennessee,

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VITA

Arijit Ganguli, son of Bimal Ganguli, was born on June 25, 1974, in Mumbai, MS, India. He graduated with a Bachelors of Pharmacy degree from the S. N. Institute of Pharmacy, Amravati University, India, in 1996. He received his Master of Business Administration degree from the University of Pune, India, in 1999.

Arijit started his professional career in pharmaceutical sales and marketing with Gufic India Ltd. in 1996, and later with Hoechst Marion Roussel (currently known as Sanofi Aventis). After pursuing his MBA from Pune University, India, he took to global marketing with Sigma Laboratories in 2000 as Senior Executive – Exports. In 2002, he joined Dana Drugs Limited, Nigeria, as Marketing Manager, and handled their pharmaceutical operations in the West African region. In 2005, he joined Goldshield Group Plc; a UK-based pharmaceutical company, as Business Development Manager, and was responsible for developing their business operations in the South East Asian countries.

Arijit has been in leadership positions throughout his career path. He served as President of the ISPOR University of Tennessee Student Chapter (2008-2009). Arijit was awarded the 'ISPOR Distinguished Service Award' for his extensive contribution to the ISPOR Student Network and as the Chair of the ISPOR Student Network Finance Committee. He was also the founder member of ISPOR journal club at Health Outcomes and Policy Research division, University of Tennessee Health Science Center, Memphis.