PUERTO RICAN ADOLESCENTS STRIVING TO LIVE A NORMAL LIFE WITH HIV: A GROUNDED THEORY

by

Janet Rodríguez

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A Dissertation Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

2009
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SIGNED: Janet Rodriguez ___________________
ACKNOWLEDGMENTS

Life is a journey, and on that journey there are many paths that can be chosen; and each of us must discover the meaning and purpose of the particular path we choose. Why we are here, at this place and moment in history? Sometimes we choose a path because it provides a challenge, or because we want to make a difference, or to change the priorities of our life, or simply to get to a destination illuminated only faintly by faith.

In 2004 I started to choose a path to make things in my own life different, and because I needed a challenge. I felt the need to begin a quest to discover what more I could do to improve nursing on my island of Puerto Rico. In 2005 I chose to start walking a path that the University of Arizona, College of Nursing (CON) allowed me to begin. This path gave me the opportunity to acquire knowledge, personal growth and a PhD.

As always, we cannot walk alone on a path with success. Success rarely comes when you work alone. At least some guidance is necessary. As I walked along my chosen path I met beautiful and kind people who have helped me define the goals of my quest. They gave me knowledge, wisdom, their experience, advice, challenges, their time, patience and many other gifts that were essential for me to successfully determine the direction of my chosen path.

I am and always will be very and deeply thankful to all the faculty and non-faculty of the CON who supported me in all ways while I began my chosen path. I can start with Dr. Joyceen Boyle for her orientation letter in 2004 that definitively made me choose the University of Arizona, College of Nursing as the place to begin my quest. Thank you for the letter, which I still have, and for the few but very important short conversations we had during RISE and WIN.

I am very blessed that Dr Sandra Cromwell was on my path. Thank you for your stimulating words that came at a moment when I was wondering, “Why am I here and what do I really want?” Thank you, Dr Kathie Insel, for the time you spent on my committee. I hope someday soon I can cook for you and we can talk about and do work together on adherence. I will always admire your work on adherence.

I wish to acknowledge and express my deep gratitude to Dr. Elaine Jones, my advisor and dissertation chair, who constantly supported me and provided her guidance, empathy, understanding, and patience during my doctoral studies. Without you I could have never walked my path. You were the most influential and caring professor throughout my doctoral studies. You were always there for me. I will always be indebted to you.

Thank you, Dr. Janice Crist, for being part of my committee, for always asking how I was doing and for your availability. You always made me think things through more than once. Also for the time we spent together having lunch, speaking in Spanish and for introducing me to Matilde. Although I was not always there on campus, I knew you were thinking about me; and you let me know that through your e-mails. I would not be as far along my path if it wasn’t for you.

Thank you, Dr Mary Koithan, because when I needed a person on my committee you said yes. Your knowledge and insights on my proposal and final dissertation were truly appreciated.

I also wish to acknowledge the non-faculty members of the CON. When I called, you were always available to help me and answer my questions. Not only did I need the CON faculty to walk my path; you were also very essential on my path. People like all of you make the CON a place to never forget and to always be missed.
I wish to thank the staff of the University of Puerto Rico, Medical Sciences Campus, School of Medicine, GAMMA Clinic, especially Dr. Irma Febo, Iraida Salabarría, Ruth, Elizabeth Román and Cathy for their trust, support, cooperation and willingness to help me do this research in their clinic. I am indebted to the GAMMA Clinic.

I wish to thank my two dearest friends. First is Marta Rivero, for your knowledge, guidance, unconditional support day and night, and friendship. You encouraged me to think and to complete this PhD and you will always be my example to follow in nursing. Second, Nancy Davila; because I pushed you to do this with me, although you made your own decision and we did it together, under pressure and with tears; we began this quest and finally WE DID IT! Your support and friendship will always be in my heart.

Finally, I would like to express my deepest Thank You to my family: my mother, Rita with her prayers; my daddy, Agapito; my sister, Myriam; my brother, David; my nieces Francis and Michelle; my nephew, Robertito; and my community family of Monte Claro who always were asking when I would be finished so that they can have a party and call me Dr. Rodriguez. Your love, support and constant encouragement provided the energy I needed to keep going.
DEDICATION

Throughout my life and I have had and still have some men that are very important in my life. At this moment, in my life, I wish to dedicate this dissertation to two of the most important men of my life, my husband, Fernando and my son Fernando Luis alias Fernandito, who for so many years and during my studies provided me with constant support, patience, understanding, laughter and the courage to keep following my quest and dream. Without these two men I would not had the energy to keep this dream. “My dearest son I will not use a cane during my graduation. I am still and always will be young. My life has just begun.”

I also wish to dedicate this dissertation to those very important people of my country, the HIV- positive adolescents who participated in this study and those who did not participate. I just started to walk a new path and to dedicate my time and efforts to help these adolescents during their disease. Without their willingness to participate this dissertation would not have been possible.
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ABSTRACT

According to the Puerto Rico Health Department as of January 2008, 258 cases of HIV, ages 10-19 had been reported and 224 cases of AIDS, ages 13-19 (Puerto Rico Health Department, 2008). The purpose of this research was to describe the basic social processes of medication adherence in Puerto Rican youth who are HIV positive. Three research questions were proposed: 1) What are the basic social processes of medication adherence in Puerto Rican youth who are HIV- positive?; 2) What factors influence medication adherence (or nonadherence) among HIV- positive adolescents?; 3) What behaviors indicate that the HIV-positive adolescents adhere or do not adhere to their prescribed medications? The Autonomy Development of Adolescence by Steinberg provided the theoretical framework for this study. Grounded theory was used to study 13 Puerto Rican HIV-positive adolescents. Data collection included semi-structured, in-depth interviews, field notes, participant observation, and a demographic questionnaire. A substantive theory Striving to Live a Normal Life, with the core category of normal emerged from data analysis. Striving to Live a Normal Life explains how these Puerto Rican HIV-positive adolescents try to integrate their HIV status and treatment with their lives. These adolescents concentrate their lives on striving to live a normal life. A variety of ways is used to deal with HIV and has helped them visualize themselves as a normal adolescent with a normal life. Because they see themselves having a normal life, taking or not taking their medications for HIV is also seen as a normal part of their lives. This study suggests the beginning of understanding the concept and process of normalization in this population. These findings support the findings in a study done with HIV–positive adolescents from France in
which the concept of normality was related to their lives. It also informs interventions to promote improved medication adherence among Puerto Rican youth who are HIV–positive.
CHAPTER ONE: INTRODUCTION

The purpose of this research was to describe the basic social processes of medication adherence in Puerto Rican youth who are HIV-positive. In order to understand the context of the research, background information is first presented about the history and culture of Puerto Rico. Next, a description of the disease process and current treatment options is provided, including the epidemiologic status of HIV-positive youth in Puerto Rico. This is followed by a) statement of the problem addressed by this research; b) the purpose and research questions; c) definition of terms; d) the significance of the research to nursing.

FIGURE 1. Map of Puerto Rico

Overview of Puerto Rico

The following pages discuss the geography, history, culture and economic aspects of Puerto Rico. A description of the health care system of Puerto Rico, and of the Puerto Rican youth will complete this part of chapter one.
**Puerto Rico Geography**

Puerto Rico (PR) (Figure 1) is a small island located in the northeastern Caribbean Sea, east of the peninsula of Haiti and the Dominican Republic, and between the Caribbean Sea and the North Atlantic Ocean. The total area of the island is 3,508 square miles. The maximum length from east to west is 110 miles, and with a maximum width from north to south of 40 miles. PR is approximately three times the size of Rhode Island (Porter & Prince, 2006).

Puerto Rico has 78 municipalities. These municipalities are subdivided into barrios, and those into sectors. Other Puerto Rican territories are such very small uninhabited islands as Mona, Monito, Desecheo and Caja de Muertos. Numerous small cays lie offshore of PR (Porter & Prince, 2006).

Concerning the political division, PR has 8 senatorial districts, 40 representative districts and 78 municipalities. The major cities are San Juan (the capital), Ponce, Mayaguez, Carolina, Arecibo, Bayamón, Guaynabo, Aguadilla, Cayey, and Fajardo. The majority of the municipalities’ names were derived from the language of the Taino Indians, indigenous to PR (Porter & Prince, 2006).

**Puerto Rico History**

Puerto Rico (PR) was discovered by Christopher Columbus on November 19, 1493. At the time it was discovered, the island was populated by Taino Indians. These Taino Indians were a subgroup of the Arawakan Indians, a group of American Indians in northeastern South America. They lived in Cuba, Jamaica, Haiti, Dominican Republic and PR by the time Christopher Columbus discovered America in 1492 (Wilson, 1999). They lived in theocratic kingdoms and had a hierarchically arranged named “caciques.” They were also divided into three
(3) social classes: the “naborias”, the work class; “nitainos”, the noblemen, and “bohiques” or priests and the “caciques” or chief (Wilson, 1999).

Physically the Taino Indians were bronze-colored, of average height, with dark, flowing, coarse hair and large and slightly oblique dark eyes. Men went naked or used a piece of cloth called “nagua”, single women went naked and married women wore an apron. Taino Indians worked in agriculture, and hunting, as sailors and, fishermen, and as canoe makers and navigators (Wilson, 1999).

After their discovery in 1493 when Juan Ponce de León took possession of the island in 1509, there were about 20 villages or “yucayeques” of Taino Indians in the island. Although there are no reliable documents from that time, anthropologists estimate that there were between 20,000 and 50,000 Taino Indians in 1508. Due to diseases, maltreatment, flight, and rebellion this decreased the number of Taino to 4,000 by 1515. In 1544, a bishop counted only 60 and this was the last count (Wilson, 1999).

The Taino culture died out during the 16th century but along with the Spaniards and the African slaves brought to the island by Spain all lived on the island. Because of this, the population of PR is a mix of Spanish, African, and Taino Indians.

Although there were no more Taino Indians, Puerto Ricans continue with some of their customs. For example the use of the hammock (“hamaca”) to rest, musical instruments such as “maracas”; names of some towns such as Humacao, Guaynabo, and Guayama; names of some trees and fruits such as “maní”, “aji” and “yuca”; and names of fishes and birds such as “mucaro”, and “manati”. Finally many superstitions and legends from the Taino still influence the Puerto Rican people (Wilson, 1999).
During the 16th century more Spanish came to PR and started to settle. A fortress named “San Felipe del Morro” and two hospitals were built. A sugar cane processing plant was also built and sugar cane became the most important agricultural product. Slaves were brought from Africa to help in the settling. Also during this century more than two hurricanes attacked the island killing many people and leaving it with some extensive damage. During this century the British and French attacked the island in order to possess it because they wanted control of America like Spain had it (Morales, 1984).

By the 17th and 18th centuries the island continued to progress as more Spaniards came to settle. These centuries were also marked by more attacks on the island. Puerto Rico was attacked by the Dutch, and the British. A census done in 1795 showed a total population of 44,883 of which 5,083 (11.2%) were slaves. In 1783, Fray Íñigo Abbad y Lasierra published in Madrid the first book about the history of PR from 1493 to 1783 (Morales, 1984).

During the 19th century, PR had many social and political changes. More “pueblos” were founded, such as Mayaguez, Aguadilla, and Fajardo. Delegates were named from Spain and the economy was progressing. Sugar, coffee, and tobacco were the main products. Free land was given to the people from Spain who wanted to immigrate to the island promoting that more Spaniards came to PR. By mid - 19th century schools were officially founded, and the telegraph was introduced (Morales, 1984).

By 1860, the population was 583,308. Of these 300,406 (51.5%) were white and 282,775 (48.5%) were persons of color including those of primary African heritage, “mulatos”, the mix of black and white people and “mestizos,” the mix of Spanish and Taino Indians. The majority of the population was illiterate (83.7%), lived in poverty and for whom agriculture was the main
source income. By this time, PR had started to struggle for autonomy. In 1868, people from Lares revolted against Spain and although it was a significant revolution, it was well controlled by Spanish authorities. This set up the creation of political and social reforms. In 1870, the first two political Puerto Rican political organizations were founded. In 1873, the Spanish National Assembly abolished slavery in PR. Finally, in 1897 and through the Autonomic Charter, Spain gave political and administrative autonomy to PR (Morales, 1984).

In May 10, 1898, Spain attacked a United States (US) ship named the USS Yale that was in PR. On May 12, a group of 12 US ships attacked San Juan. In July, American troops landed in the island. There was opposition but by the end of August, PR was under the control of the US. This event was called the Spanish–American war. By the end of the 19th century, Spain had given PR, the Philippines, and Guam to the US, and renounced all claims to Cuba exchange for twenty million dollars ($20,000,000) (Morales, 1984).

During the first half of the 20th century, PR was marked by the struggle to obtain more democratic rights from the United States. The Foraker Act of 1900, established a civil government, and the Jones Act of 1917, granted Puerto Ricans U.S. citizenship. In 1952 democratic elections were held for the first time. As of now, PR is a Commonwealth of the United States. The differences between being a commonwealth and one of the states are that Puerto Rican do not vote for the President of the U.S. nor for representation on the Senate nor House of Representative, exemption from some areas of the Internal Revenue Code and no assignment of some revenues reserved for the states (Rivera, 2008).

“Because PR is a Commonwealth of the United States, they (US) control: the interstate trade, customs administration, foreign relations and commerce, control of air, land and sea, immigration and emigration, nationality and citizenship, currency, maritime laws, military service, military bases, army, navy and air
force, declaration of war, constitutionality of laws, jurisdictions and legal procedures, treaties, radio and television, agriculture, mining and minerals, highways, postal system, social security, and other areas generally controlled by the federal government in the U.S” (Rivera, 2008).

By 1950 the industries had become the main source of economic income. Encouraged by duty free access to the U.S. and by tax incentives, U.S. firms invested heavily in PR in the 1950s. As a result, Puerto Rico's export and import has prospered, nearly doubling over the years (Rivera, 2008).

Because the economy has suffered budget cuts from the U.S., the Puerto Rican economy has depended heavily on the tax incentives given to U.S. mainland companies and on federal transfers. Puerto Rico has very few natural resources of economic value and its economy relies mainly on Federal Aid from the United States Government, which depends on the industrialization programs and the tax incentives that the U.S. offers (Rivera, 2008).

Important industries that help in the economy of Puerto Rico are: pharmaceuticals, electronics, textiles, petrochemicals, processed foods, clothing and textiles. Dairy production and other livestock products are the main source of income in the agricultural sector. The principal livestock are cattle, pigs and poultry. Tourism has traditionally been an important source of income for the island, with estimated arrivals of nearly 4.9 million tourists in 2003, and the tourism industry employees over 60,000 people (Rivera, 2008).

Puerto Rico has uses its own statistical poverty level, which is significantly lower than the one proposed by the U.S. Department of Health and Human Services and the U.S. Census Bureau. The population living below the poverty level in Puerto Rico was 44.6% by year 2000 (Rivera, 2008).
Because Puerto Ricans are American citizens, the island does not have a President. It has a Governor who it is elected every four (4) years. The government is divided into two chambers: the House of Representatives and the Senate. Also, the government of PR has three powers: the executive power, exercised by the Governor; the legislature power, exercised by the Senate and the House of Representatives; and the judiciary power, exercised by the Supreme Court that is composed of seven judges named by the Governor. Each municipality has a mayor elected every four (4) years. Finally, PR has a resident commissioner in the Congress of the US that has a voice but does not vote.

*Puerto Rico Culture*

In brief, traditions and heritage in PR concerning architecture, craft, arts, food, music, literature and folklore were all originated by the Taino Indians, the Spaniards and the slaves from Africa. The following is a discussion of the concepts of familism, respect, “machismo”, and “simpatia” in the island.

*Familism*

Puerto Rican culture has been influenced the traditions of the three main ethnic groups: the Spanish, Africans and our Tainos’ Indians. There are many similarities with other Hispanic groups, as well as some unique aspects connected with the island’s history. Family is the foundation of the Puerto Rican social structure. The word ”familismo” is a Puerto Rican Spanish word that means close family connections, and it emphasizes the concern for the well being of the family. Puerto Ricans continue to follow the cultural characteristics of familism as a priority (Serpa, 2006). Familism is about the importance individuals give to the family in terms of feelings of loyalty, reciprocity, and solidarity and it is one of the most enduring and distinctive
characteristics among Puerto Ricans. Interactions between family members and others are expected to be courteous, honorable and considerate. Family honor is of primary importance to Puerto Ricans, and they value an extended family, or modified extended family, including cousins, aunts, uncles, grandparents, godparents and close friends (Serpa, 2006). Among the characteristics that the families exhibit are loyalty, respect, generosity, helpfulness, responsibility, sacrifice and hard work.

*Machismo*

Puerto Rican families are often patriarchal, with men having the responsibility to sustain the family and an authoritarian role (Marin & Marin, 1991). “Machismo” is a socially and reinforced set of behaviors delineating male roles in the Hispanic culture (De La Cancela, 1986). Machismo expects that the women will stay home with the children and assume the responsibility of taking care of them.

*Respect*

Respect is another cultural characteristic of the Puerto Rican. Respect will dictate deferential behavior toward others based on age, gender and authority (Arredondo, et al., 1996). It is expected that older adults will be respected by the younger. Avoiding eye contact with authority figures is a sign of respect in our culture. It is also expected that the children will not contradict, argue or disagree with the adult and elder members of their family.

*“Simpatia”*

Kindness or “simpatia” for Puerto Ricans is very important. Puerto Ricans try to avoid the conflict and confrontation and repress the anger and aggression (Applewhite, 1998).
“Simpatia” describes the value placed on positive interpersonal interactions and being agreeable (Applewhite, 1998; & Marin & Marin, 1991).

Puerto Rico Health Care System

The Government of Puerto Rico initiated a health reform process in 1993, aimed at monitoring the delivery of public and private health services, eliminating discrimination in medical care, ensuring access to quality services for all, through managed care, and redefining the governmental function as the sole indigent medical service provider. The Puerto Rico Health Care system, called Puerto Rico Health Reform, is a health care program run by the government that provides medical and healthcare services to the indigent and impoverished citizens of Puerto Rico (Department of Health, 2008).

The health care is provided by contracting private health insurance companies, as opposed to the traditional system of government-owned hospitals and emergency centers. This health care system requires the service population to be divided into geographical areas with each area assigned to a sole insurance carrier by means of a services contract awarded through competitive bidding and proposals. The Reform is administered by the Puerto Rico Health Insurance Administration and, as of December 31, 2005, provided healthcare coverage to over 1.5 million Puerto Ricans (Department of Health, 2008).

Puerto Rican Youth

By year 2006 there were 302,626 children and adolescents aged 10 to 14 years old and 296,387 adolescents ages 15 to 19 (Puerto Rico Planning Board, Social & Economic Planning, Census Office, 2009). According to the 2000 Census, 58.4% of children under 18 years old live below the poverty level (Puerto Rico Planning Board, Social and Economic Planning, 2000).
School dropout rates range from 14% to 51% and one in five students between the ages of 14 and 20 was at least two years behind in grade level in 2000 (Cordero & Pascua, 2004).

In 2004, the primary leading causes of death in children and adolescents aged 10 to 14 years old were, in descending order, accidents, homicides, neoplasms, and respiratory diseases. The first two causes of death in the group aged 15 to 19 were homicides and accidents (Department of Health, 2004).

Results of a recent study that describe the values of Puerto Rican youth suggested the importance of family values the Puerto Rican youth (Vales, 2003). The research surveyed, in 2003, 4,591 youth aged 13 to 29 years old using the Profile and Necessities of the Puerto Rican Youth Instrument (Vales, 2003). The following key findings describe the priorities of our Puerto Rico’s youth population: a) 31% family; b) 12.5% occupational; c) 12.2% educational; d) 11.9% physical and mental health; e) 11.5% sport/recreational; f) 9.6% security; g) 4.1% social; h) 3.6% religious; and i) 3.5% environmental (Vales, 2003).

Puerto Rican adolescents are optimists; family is held to be important, followed by the necessity to have a job and an education. It can be said that cultural influences in our adolescents have led many of them to decide that family, having a job and an education are very important in life.

HIV/AIDS in Adolescents

Introduction

It has been more than 25 years since the HIV virus was diagnosed in humans. The epidemic was initially reported among gay people and was named gay-related immune deficiency (Lyon & D’Angelo, 2006). The HIV/AIDS epidemic spread to other populations of
all ages, including adolescents. This section provides an overview of the pathophysiology of HIV/AIDS, information about transmission, (especially among adolescents), a review of the usual treatment for HIV and the importance of adherence to medication regimens for long-term survival.

**Pathophysiology**

HIV is a lentivirus, a subgroup of the retroviruses. This virus is known for its latency, persistent viremia, infection of the nervous system, and weak host immune responses (Spiegel & D’Angelo, 2006). When this virus invades the body, it may enter any cell but it has a propensity to infect and kill cells of the immune system, particularly the CD4 or T-cells (T-lymphocytes). It binds to the CD4 cells. This virus actively replicates itself by generating a DNA copy by reverse transcriptase. Viral DNA becomes incorporated into the host DNA for further replication (Spiegel & D’Angelo, 2006). This leads to immune system damage and results in susceptibility to opportunistic infections such as cancer, neurologic diseases, tuberculosis, wasting and death (Uphold & Graham, 2003).

CD4 count is used to assess immune system status, susceptibility to opportunistic infections and for defining AIDS (CD4 <200), among other things. The lower the CD4 count the weaker the immune system. The range of CD4 cells is between 500 and 1500 CD4 cells/mm³. HIV positive people have counts < 500 and people with AIDS < 200 CD4 cells/mm³ (Gallant & Hoffmann, 2007; Nassar, Keiser & Gregg, 2006).

HIV viral load tells how active the HIV disease is and also indicates whenever the medication regimen is working. Results are reported as the number of HIV copies/ml of blood. When treatment for HIV is effective it is expected that HIV replication has been suppressed to
the point where the amount of active HIV is below the sensitivity of the HIV viral load test (Cichocki, 2007; Gallant & Hoffmann, 2007; Nassar, Keiser & Gregg, 2006).

Transmission

The HIV epidemic in adolescents is different from the adult epidemic. These differences are found in the transmission, clinical courses, and services needs. There are three predominant ways of transmission of HIV in adolescents: 1) transmitted from mother to fetus or newborn during the perinatal period; 2) transmitted through blood products e.g., transfusions; and 3) transmitted through sexual contact with an infected person. Transmission through IV drug use (often shared needles) has never been a major route of infection in adolescents (Smith Rogers, 2006). Transmission perinatally has decreased to less than 3% since HIV-positive women have been prescribed antiretroviral therapy (ARVT) during pregnancy (Jaspan & Garry, 2003).

Signs, Symptoms and Clinical Course

The most common signs and symptoms presented in adolescents with HIV are: fever, fatigue, lymphadenopathy, arthralgias, rash, diarrhea, nausea, vomiting, thrush, weight loss, hepatosplenomegaly, and some neurological disorders (Nassar, Keiser & Gregg, 2006; Uphold, 2003).

The clinical course of HIV in adolescents will depend on the mode of transmission, their general health, nutrition, socioeconomic status, and other infectious diseases (Spiegel, & D’Angelo, 2006). In adolescents, even with excellent care, HIV infection may affect metabolic and endocrine function and alter hormonal systems involved in the control of growth and puberty development (Buchacz, et al., 2003).
The age of the first infection is an important predictor of the duration of the time to an AIDS diagnosis; that is the earlier the age of an HIV diagnosis, the longer the period until an AIDS diagnosis (Rosenberg, Goedert & Biggar, 1994). There is evidence that HIV-positive adolescents have a better immunologic reserve than adults, important for their response to HIV and one of the reasons why full adherence to ARVT is important (Smith-Rogers, 2006). Adolescents have a larger proportion of early precursors of T lymphocytes than adults. This means that if the ARVT decreases the progression of HIV virus, then there will be more T lymphocytes and this can fight off a broader range of opportunistic and infectious agents (Smith-Rogers, 2006).

Treatment

ARVT goals for HIV-positive adolescents are to: reduce HIV-related morbidity and mortality, improve quality of life, preserve and restore immunologic function, and maximally suppress viral load (Department of Human and Health Services - Panel on Antiretroviral Guidelines for Adult and Adolescents, 2007). Once a person is diagnosed as HIV- positive, timing of ARVT will depend on the CD4 count and the presence of opportunistic infections. It is recommended that the adolescent start therapy when their CD4 cell count drop below 350 cells/mm³ or if they have an AIDS- defining illness. Other recommendations are: 1) when the CD4 count is below 200 cell/mm³ and a history of an AIDS- defining illness; b) in pregnant HIV-positive women; c) patients with HIV associated nephropathy; and d) in patients coinfected with hepatitis B (Department of Human and Health Services-Panel on Antiretroviral Guidelines for Adult and Adolescents, 2007).
Treatment for HIV-positive adolescents includes a variety of medications, each with specific functions that will interfere with the virus in making a copy of itself in the human cell. HIV needs certain proteins supplied by the infected person in order to make copies. One of those proteins is an enzyme called protease. Protease inhibitors are medications that block the functioning of that enzyme and this will make the HIV virus unable to mature; and therefore it cannot make more copies of itself. Examples of some protease inhibitors used in HIV-positive adolescents are: Viracept, Kaletra, Norvir, Invirase, Agenerase, and Lexiva (Cichocki, 2007; National Institute of Allergy and Infectious Diseases-National Institute of Health, 2007).

Another type of antiretroviral used in HIV-positive adolescents is the nucleoside reverse transcriptase inhibitors (NRTIs), or “nukes” as they are called. These NRTIs blocks reverse transcriptase, preventing the transformation from RNA to DNA. Without the DNA, HIV is unable to make functional copies of itself. Examples of NRTIs are Combivir, Epivir, Zerit, AZT, and Emtriva (Nassar, Keiser & Gregg, 2006; National Institute of Allergy and Infectious Diseases-National Institute of Health, 2007).

Another type of antiretroviral used in HIV-positive adolescents is the non-nucleoside reverse transcriptase inhibitors (NNRTIs). This medication also interferes with HIV replication like the NRTIs, but they block the reverse transcriptase in a different way. Examples of NNRTIs are Viramune, Sustiva, and Rescriptor (Nassar, Keiser & Gregg, 2006; National Institute of Allergy and Infectious Diseases-National Institute of Health, 2007). A final type of antiretroviral is the entry inhibitors. These work by not allowing the HIV virus to enter into the CD4 cell, by blocking the HIV replication. Examples of entry inhibitors are Fuzeon and Maraviroc (Cichocki,
Although ARVT has prolonged the life expectancy of some of the HIV-positive adolescent population these medications have potentially adverse effects. Some of the most common adverse effects are: a) lactic acidosis and hepatic steatosis from treatment with NRTIs. This adverse effect is associated with high mortality rate. b) Hepato-toxicity is another adverse effect. c) Hyperglycemia, glucose intolerance, insulin resistance, new onset diabetes mellitus, diabetic ketoacidosis, and exacerbation of pre-existing diabetes mellitus are also adverse effects strongly associated with PI use (Uphold, & Graham, 2003). d) Lipodystrophy, hyperlipidemia with elevation of total serum cholesterol, increased spontaneous bleeding episodes, osteonecrosis, osteopenia, and osteoporosis and, skin rash are also adverse effects of ART (Uphold, & Graham, 2003).

Antiretroviral therapy regimens are tailored to the individual adolescent and depend on various factors: mode of transmission, Tanner staging of puberty, body mass, and chronological age (Cichocki, 2007; National Institute of Allergy and Infectious Diseases-National Institute of Health, 2007). HIV infection can be treated with ARVT. Treatments for this life-threatening illness have progressed significantly, and mortality rates have decreased in this adolescent population. Although ARVT has been shown to suppress HIV, strengthen the immune system and reduce AIDS associated morbidity and mortality (Vittinghoff, Scheer & O’Malley, 1999), treatment for HIV/AIDS has resulted in decreased mortality over the years, and more recent treatment regimens involve increasingly more complex schedules, the challenge of taking ARVT for life remains daunting. In order to prolong life expectancy while living with HIV, medication
adherence plays an important role. Adolescents, the population of interest for this dissertation, have mainly become infected through blood, perinatally and sexual encounters (Smith-Rogers, In Lyon & D’Angelo, 2006). A high level of adherence, estimated at 95%, is necessary to maintain adequate therapeutic levels (Carpenter, Cooper, & Fischl, 2000; Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006).

Many HIV-positive adolescents do not take antiretroviral medications, even when that treatment is clinically indicated and advised (Schwarz, Henry-Reid, Houser, Ma, & The Adolescence Medicine HIV/AIDS Research Network, 2001). Difficulties with adherence to ART have been shown to be prevalent among adolescents (Murphy, Wilson, Durako, Muenz, & Belzer, 2000). Reasons for not adhering properly are patient related, family related, treatment related, health care providers related, and disease related. Adherence among HIV-positive adolescents ranges between 28.9% and 100%. (Belzer, Fuchs, Luftman, & Tucker, 1999; Martinez, et al., 2000; Murphy, et al., 2003; Naar King, et al., 2006; Reddington, et al., 2000;; Wiener, Riekert, Ryder, & Wood, 2004).

Challenges in Providing Health Care for HIV Positive Adolescents

Providing health care for an adolescent can be challenging because they are no longer children, but not yet adults. If the adolescent has a chronic disease, giving them, and getting them to accept care can become even more challenging. The following section discusses some of the challenges of providing health care for adolescents with HIV.

Disclosure

Because of the lack of treatment options in the early 1990s, many children who were perinatally infected with HIV were not told of their HIV status until their teens. With the advent
of ART, many of these children now are surviving into adolescence, and parents and providers must decide whether or not to disclose the HIV status to the adolescent. Studies suggest that adolescents who know their HIV status have higher self-esteem than those who are unaware of their status, and this helps in the provision of health care because the adolescent is able to participate in and cooperate with treatment (Committee on Pediatric AIDS, 1999). Adolescents who do not know their HIV status have difficulty understanding why they have to take so many pills and go to clinics when they are feeling well (Gerson, et al., 2001).

HIV-positive adolescents who know their status are faced with the decision of whether to keep the virus a secret from family members, sexual partners, and peers. This can cause feelings of loneliness, denial, and depression. Fear of disclosure and subsequent rejection can cause some adolescents to avoid seeking the health care they need, which then makes it difficult for them to cope with the disease (Session, 2002). This fear can also isolate them from potential sources of support (Committee on Pediatric AIDS, 1999).

*Developmental Stage*

Adolescents often feel invulnerable and immortal, but at the same time struggle with developing a sense of their own identity and while worrying about trying to appear normal (Session, 2002). Adolescents are concerned about being physically attractive, while dating and developing close friendships with peers. HIV-positive adolescents want to establish a sense of themselves as normal and not as being sick or different from their peers. They do not want to be reminded of their disease (Session, 2002). Because of this, HIV-positive adolescents can simultaneously experience fear, denial and rejection, making it difficult for them to seek health care.
HIV-positive adolescents who are asymptomatic and who are still concrete thinkers may have difficulty accepting their diagnosis because of difficulty in understanding what it is to have HIV. This too can be a challenge to the provision of appropriate health care (Hoffman, Futterman & Myerson, 1999).

**Stigma**

HIV/AIDS-related stigma and discrimination negatively affects behaviors, HIV care-seeking behavior and the provision of quality of care (Raizada, Monika Gupta & Somasundaram, 2004). For many HIV-positive adolescents, fear of stigmatization or discrimination creates a barrier to seeking care or counseling (Augustine, 2002). The stigma of HIV leads families to keep the diagnosis a secret from their child, making disclosure to the adolescent patient more difficult. Stigma and disclosure fears also act as barriers to the provision of care (Grubman, et al., 1995).

HIV/AIDS stigma is a significant issue for HIV-positive adolescents, who are negotiating the transition from adolescence into adulthood. Stigma can interfere with provision of health care, willingness to accept the disease and willingness to disclose to others. For HIV-positive adolescents, stigma has a variety of domains including personalized stigma, disclosure concerns, negative self-image and concerns with public attitudes about HIV. Stigma can interfere with health and risk behaviors as well as the quality of life of youth infected with HIV (Wright, et al., 2004).

**Lack of Social and Family Support**

HIV-positive adolescents are a unique group who face more challenges and barriers than the general adolescent population. They can benefit from having people around them who care
about them, and value and love them. The lack of social and family support linked to that results in emotional distress, behavioral problems and poor mental health can make it difficult for many HIV-positive adolescents to seek health care (Augustine, 2002).

Because HIV is often a multigenerational disease, the family structures of many HIV-positive adolescents have changed (Lewis, 2001). In many cases, adolescents do not live with parents. Some live with only one parent and the majority live with extended family because both parents have died of AIDS. In a study among HIV-positive children and adolescents, 76% of the children were orphaned because AIDS, 26% lived with one or both parents, 60% lived with extended family, 7% with kinship family, and 7% shuttled between adopted family and foster care (Grubman, et al., 1995). Changes in family structure can lead to a lack of family and social support, which leads to not seeking health care.

Social support is an important factor in health maintenance (Helgeson & Cohen, 1996). It may influence health by decreasing stress, influencing affective states and/or changing health behaviors (Cohen, 1988; Connell, Davis, Gallant, & Sharpe, 1994). HIV-positive adolescents have identified the importance of social support in their survival, coping and general livelihood. Having support from people who are informed and nonjudgmental about the disease has resulted in positive outcomes for HIV-positive adolescents. Not having this support can cause social, emotional and health effects (Conner, Wilson & Lyon, 2006).

Disparities to Appropriate Health Care Services

Health disparities are defined as "differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States" (National Institute of Health, 1999). Health disparities can be
attributed to possible "differences in risk factors, lack of access to health care, inadequately targeted prevention messages, and cultural differences between the health care system and the populations it serves" (Health Resources and Service Administration, 2000).

HIV-positive adolescents are faced with a health care system that is not sufficiently prepared to address the needs and developmental health care required by this population. There is a necessity to provide health care clinics with specific interventions unique to this population, based on preliminary needs assessments and specific competence in the culture of adolescents. These services must be comprehensive, continuous, integrated and must include outreach, testing and treatment (Johnson, et al., 2003).

HIV-positive adolescents in PR, and elsewhere, frequently lack financial resources to pay for their own medical care, and have insurance that limits their access to many types of care (Szekeres, 1999). Often these adolescents do not have money to pay for transportation to the clinic or for food for the day that they are traveling to and from a distant clinic (Rodríguez & Holzemer, 2007). They may have no access to health care services because they do not live in that locale close enough to a provider. Adolescents may be unable, by law, to consent to health care services on their own because they are minors (Szekeres, 1999). Adolescents often do not have an in-depth knowledge of the health care system, and they may not know how to search for care associated with HIV. Fear and mistrust of the health care system act as additional barriers to adolescents seeking care (Szekeres, 1999).

In order to decrease disparities in health care and provide appropriate health care to HIV-positive adolescents, health systems need youth-friendly clinics, as well as providers who understand the particular needs of adolescents and who want to work with them. Ideally, health
care services for HIV-positive adolescents would have youth-oriented HIV expertise and would provide appropriate health, social and preventive services (Szekeres, 1999).

Dealing with a life threatening disease during adolescence can be overwhelming. Providing health care to HIV-positive adolescents can be difficult and complicated for both the adolescent and the health care providers. This population should have the right to expect a high quality of health care that is sensitive to their needs.

Researchers have identified a number of other challenges related to providing health care to HIV-positive adolescents. These include mistrust of health care professionals, difficulty negotiating complex health care systems, complicated medical regimens, a shortage of providers with expertise in both HIV and adolescent medicine, and concerns about confidentiality. Fear, denial, and cultural perspectives may also contribute to a HIV-positive adolescent’s reluctance to seek for care (Brown, Lourie, & Pao, 2000; Futterman, Chabon, & Hoffman, 2000).

HIV-positive adolescents may choose not to seek needed services or may refuse if they perceive a lack of respect. Fear of a loss of confidentiality is another major obstacle to many adolescents seeking health services. The issue is particularly important for HIV-positive adolescents, who may experience rejection, discrimination, and/or violence if their confidentiality is broken (Augustine, 2002).

Housing is another issue when providing health care to an HIV positive adolescent. Some are put out of their homes when their HIV status becomes known and may assume risky behaviors, such as prostitution, in order to survive on the streets (Augustine, 2002). HIV positive adolescents are more likely to follow complex medical regimens and to remain healthy if they have a safe place to live and a place to keep medications and other necessities. If an HIV positive
adolescent is not living in a stable and safe environment, seeking health care services will not be his/her priority.

Providing health care to adolescents can be a difficult task, and it is made even more difficult when the adolescent has a chronic illness such as HIV. In order to provide high quality, effective care to these patients, providers must take into consideration not only the adolescent’s HIV status, but also issues related to physical, cognitive, emotional, and autonomy development, and the context of the HIV-positive adolescent’s life. Only with a full understanding of these issues will providers be able to fully address the needs of their HIV-positive adolescent’s clients.

HIV/AIDS in Puerto Rican Youth

According to the Puerto Rico Health Department, by September 2009, 261 cases of HIV, and 265 cases of AIDS, ages 13-19 (Puerto Rico Health Department, 2009).

Health Care Services Provided in Puerto Rico for HIV Positive Adolescents

Health care services to HIV positive adolescents who live in PR are provided through the Puerto Rico Pediatrics AIDS Comprehensive Care and Family Network. This program was founded in 1988 and it is supported by the federal government under the Health Resources & Services Administration (HRSA), Ryan White Funding Part D and the Government of Puerto Rico. Services are provided to every HIV-positive women and to HIV-positive children and adolescents until they are 24 years old. This program provides services at nine clinics throughout the island. These clinics are located in Arecibo, Bayamon, Caguas, San Juan, Fajardo, Mayagüez, Ponce and GAMMA (Rivera-Perez, 2007).

This program provides the following services: a social worker, psychology, perinatal prevention of HIV/AIDS, community education and consumer work. Individually each service
provides specific help to this population. Specialized clinical management is offered to this population. Pediatricians and infectious disease pediatricians are available to provide treatment and care. Also clinical protocols and research clinical projects have been developed in order to manage these patients. Case management is available that provides support to the patient and the family. Their main aim is to reduce and prevent medical and social problems to the family of the patients. They provide social activities for the family and the patients such as summer camps, and a Christmas party (Rivera-Perez, 2007).

The program related to perinatal prevention of HIV/AIDS, provides services to pregnant women who are HIV-positive. These services are: education, treatment, and follow up. The program of community education provides massive educational activities to communities throughout the entire island. It also coordinates and offers training to professionals of different disciplines. The program related to mental health has psychologists who provide mental health services to this population. These services include individual, couples and family therapy, evaluations, advisements in HIV, group therapy and support. The program also works with the patient in their disclosure of HIV, adherence to treatment and living with HIV. All these services are provided depending on the problems and needs of the patients and the family (Rivera-Perez, 2007).

Problem Statement

There are a substantial number of Puerto Rican youth who are HIV positive and undergoing treatment for HIV. However, there is tremendous variation in the degree of adherence to medications. Rodriguez and Holzemer (2007) found that adherence among Puerto Rican youth with HIV ranges from 17-100%. There is little research to guide development of
interventions to promote improved adherence among adolescents with HIV, and none conducted with Puerto Rican youth. This research was the first step in improving medication adherence among HIV-positive Puerto Rican youth and thereby improving their long term survival and quality of life.

Purpose of the Research

The purpose of this research was to describe the basic social processes of medication adherence in Puerto Rican youth who are HIV-positive.

Research Questions

1. What are the basic social processes of medication adherence in Puerto Rican youth who are HIV-positive?
2. What factors influence medication adherence (or nonadherence) among HIV-positive adolescents?
3. What behaviors indicate that the HIV-positive adolescents adhere or do not adhere to their prescribed medications?

Definition of Terms

1. Acquired immunodeficiency syndrome (AIDS): This is the final stage of HIV infection. It can take years for a person infected with HIV, even without treatment, to reach this stage. Having AIDS means that the virus has weakened the immune system to the point at which the body has a difficult time fighting infections. When someone has one or more of these infections and a low number of T cells, he or she has AIDS (CDC, 2007).
2. Adolescent: (used synonymously with the word “youth” in this study): individuals who are 13 to 21 years of age.
3. Adherence: is the extent to which a client’s behavior coincides with the prescribed health care regimen determined through a shared decision making process between the client and health care provider (Frank & Miramontes, 1997).

Significance of the Research to Nursing

Results of this research, a grounded theory study of medication adherence among Puerto Rican youth who are HIV-positive, will inform interventions to promote improved medication adherence among Puerto Rican youth who are HIV-positive. This understanding will help Puerto Rican nurses and other health care providers to promote culturally competent innovative care, provide tailored approaches to meet adherence issues, eliminate health disparities and help improve the life of those Puerto Rican HIV-positive adolescents served.

Summary

Chapter one introduced the basic assumptions and background of this research. According to the Puerto Rico Health Department, as of January 2008, 258 cases of HIV, ages 10-19 had been reported and 224 cases of AIDS, ages 13-19 (Puerto Rico Health Department, 2008). There are a substantial number of Puerto Rican youth who are HIV-positive and undergoing treatment for HIV. However, there is tremendous variability in the degree of adherence to medications. Rodriguez and Holzemer (2007) found that adherence among Puerto Rican youth with HIV range from 17-100%. A high level of adherence, estimated at 95%, is necessary to maintain adequate therapeutic levels and optimal survival (Carpenter, Cooper, Fischl, 2000; Simoni, Pearson, Pantalone, et al., 2006). Because of the seriousness of this problem, this study will describe the basic social processes of medication adherence in Puerto Rican youth who are HIV-positive.
CHAPTER TWO: THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Theoretical Framework/Literature Review

The theoretical underpinnings for this research on Puerto Rican youth who are HIV-positive are drawn from developmental theories of adolescence and extant research about medication adherence or non-adherence among adolescents. The first section presents an overview of three developmental theories of adolescents relevant to this investigation: 1) Erickson’s theory of psychosocial development; 2) Piaget’s theory of cognitive development; and 3) Autonomy development. Following this overview, literature will be reviewed concerning medication adherence in HIV-positive adolescents. The chapter concludes with a summary.

Adolescence

Adolescence is the stage of development and growth that follows after the school-aged stage has finished (Pilliteri, 2007). There are three stages of adolescence: early (11-14 years), middle (15-17), and late (18-21) (American Academy of Pediatrics). It is a stage in which the human being has many changes in their physical, cognitive, moral and behavioral status that will result in becoming an adult.

This research used adolescents with HIV as the population of interest. Because these adolescents were the main reason for this research, two classical theories and a contemporary theory of adolescent development will be discussed as follows. Of those development theories, the Autonomy Development Theory according to Steinberg will served as the basis of the conceptual framework for this research and will help understand the behavior of medication adherence in Puerto Rican adolescents with HIV.
**Biological Development During Adolescence**

Biological changes associated with adolescence begin with puberty. Puberty is the period during which an individual becomes sexually mature, which is a process that includes a series of physical changes, usually between 10 and 14 for girls and between 12 and 16 for boys (National Institute of Child Health & Human Development, 2007). The main biological changes that occur during adolescence are: rapid acceleration in growth, resulting in an increase in height and weight; development of primary and secondary sex characteristics; changes in body composition, specifically, in the quantity, and distribution of fat and muscle; and changes in the endocrine, central nervous and respiratory systems (Susman & Rogol, 2004).

**Psychosocial Development During Adolescence**

Erickson developed a theory about the psychosocial development of the person. He stated eight (8) psychosocial crises over the course of the life span. He believed that the forming of a sense of identity is the chief psychosocial crisis of adolescence (Steinberg, 2005).

One of the main developmental tasks during this stage is to form a sense of identity and form close relationships with persons of the opposite as well as the same sex (Erickson, 1963). In order to form a sense of identity, an adolescent must accept his/her changed body image; establishing a value system to decide what kind of person he/she wants to be; make a career decision, and become emancipated from his/her parents (Erickson, 1963). Adolescents who do not achieve a sense of identity develop role confusion (Erickson, 1963). This can lead to difficulty functioning effectively as adults. They are unable, for example, to decide what stand to take on a particular issue or how to approach new challenges or situations. Successful resolution of this challenge will depend on the healthy resolution of the challenges that have preceded it.
The way in which the adolescent resolves the crisis of identity will have an impact on his or her struggle with the crisis of adulthood (Steinberg, 2005).

Cognitive Development During Adolescence

According to Piaget, cognitive development in adolescents moves from concrete thinking to formal operational thoughts (Piaget, 1969). Adolescence is often referred to as the period of formal operations because of the development of abstract thinking and hypothetical reasoning. This change involves the ability to think in abstract terms and the use of the scientific method to arrive at conclusions (Piaget, 1969). This allows adolescents to plan for the future, project themselves into the minds of others and imagine how others view them or their actions.

Autonomy Development During Adolescence

In 1966, Douvan and Adelson wrote about and distinguished three forms of adolescent autonomy named: emotional autonomy, behavioral autonomy and value autonomy (Douvan, & Adelson, 1966). The foundations for this were on the western societies and several adolescent developmental theories such as, Erickson’s psychosocial development of the adolescent, and Freud’s psychoanalytic theory (Douvan, & Adelson, 1966). Later in 1985, Laurence Steinberg, a psychologist with a PhD in human development and family studies, wrote and explained about these three forms of adolescent autonomy. He defined and discussed them in a more contemporary form and related to the adolescents of today (Steinberg, 1985). In his book Adolescence, now in its seventh edition, he continues to discuss adolescent autonomy with examples from today’s adolescent generation (Steinberg, 2005).

Adolescents confront issues when starting to develop the capacity to function autonomously, while keeping connections and looking for support from others when needed
(Zimmer-Gembeck, 2001). Because of this, autonomy is often a main concept in theories of adolescent development. Autonomy can be defined as a state of being independent or self-governing (Spear & Kulbok, 2004). Growing to independence from the family is part of autonomy, and also is behavioral, emotional and value components (Steinberg, 2005).

The family plays an important role in the development of adolescent autonomy. Family factors related to the development of adolescent autonomy include parenting styles, family interactions, and transitions related to the family life cycle (Pardeck & Pardeck, 1990). Emotional, behavioral and value autonomy encompass the entire process of reaching autonomy during adolescence (Steinberg, 2005).

**Emotional Autonomy**

Emotional autonomy deals with the adolescent as an individual and with his/her relationships, especially with the parents. The processes of detachment and individuation are important in acquiring emotional autonomy (Collins & Laursen, 2004; Steinberg, 2005). Emotional autonomy occurs when the adolescent realizes that his/her emotions are independent from those of the parents. For parents, the difficulty is in finding ways to encourage emotional autonomy and independence while avoiding tension and conflict. When parents and adolescents compromise and adapt during this period of change, it can be a positive time of exploration for both. Here the adolescent starts to realize that the parents are not perfect and they do not know everything. Detachment happens because they start relationships with their peers and modify those with the parents without becoming detached from their parents (Steinberg, 2005, 2001).
Individuation during emotional autonomy is related to developing a sense of identity. This sense of identity makes an adolescent a competent individual, separate from the parents. It also changes the way they see and feel about themselves (Steinberg, 2005, 2001).

**Behavioral Autonomy**

Behavioral autonomy refers to self-governance, regulation of one’s own behavior and acting on personal and independent decisions. Decision making ability, peer influence susceptibility, and self–reliance are important steps to the development of behavioral autonomy (Steinberg, 2005). Decision-making abilities improve over time. The adolescent becomes able to think in abstract ways and anticipate the possible consequences of his/her actions. They begin to recognize the value of advice from others and begin to realize that advice from others may be influenced by the other’s personal opinions (Steinberg, 2005; Steinberg & Scott, 2003).

During the development of behavioral autonomy, the adolescent realizes there are many ways to view any situation. They begin to seek out the advice of others and are capable of comparing one choice to another and thinking about the consequences of their decisions. They learn that everyone has their own biases, and they start to feel more confident in their own decision-making abilities (Steinberg, 2005; Steinberg & Scott, 2003).

Although adolescents may stop asking their parents for advice, this does not mean that they are acting on their own accord. Rather, they may be relying on friends instead. In this case, the adolescent is not being autonomous. True behavioral autonomy requires that the adolescent act on her/his own, rather than simply following others, whether they are parents or friends.
Value Autonomy

Value autonomy has to do with having independent attitudes and beliefs regarding spirituality, politics, ideology and morals. An adolescents' ability to think in the abstract helps him/her see the differences between general and specific situations, and to make judgments using higher-level thinking. Development of value autonomy means that teens take time to consider their personal value systems and explore other possibilities. In this way, adolescents come to their own independent conclusions about their values, rather then simply accepting the values of their parents or friends (Steinberg, 2005; Steinberg & Scott, 2003).

The development of emotional and behavioral autonomy occurs during early and middle adolescence while value autonomy develops during late adolescence (Steinberg, 2005). The development of these autonomies reflects progression toward becoming an adult who has a positive mental health, high self-esteem, positive self-concept and is self-motivated, self-initiating and self-regulating (Steinberg, 2005; Steinberg & Scott, 2003). Parents, peers, and teachers all play important roles in the process developing autonomy. Understanding the changes that the adolescent is facing will help him/her become a happy and productive adult.

In summary, adolescence is a developmental stage that involves transition from dependence to independence. The adolescent begins to adopt a multitude of new social and emotional roles and learns to cope with their altered bodily functions (Kyngas, 2000). It is a vulnerable time and a critical stage in growth and development (Szekeres, 1999). Adolescents with a chronic disease find it difficult to make a lifelong commitment to treatment (Positive Youth Outreach, 2000).
Autonomy Development in Adolescents with Chronic Disease

Having a chronic disease during adolescence constitutes a major challenge for the adolescent, his/her family and health care provider (Suris, Michaud & Viner, 2004). It can affect psychological development, resulting in poor adherence to treatment because of poor development of abstract thinking and planning, difficulty in imagining the future, having a self-concept of being invulnerable, and rejecting health care providers (Suris, Michaud & Viner, 2004). It can cause failure of peer relationships, social isolation, educational failure, failure of developing independent living ability and risky behaviors (Suris, Michaud & Viner, 2004).

In chronic illness, autonomy development may be related to illness control. Having a chronic illness may lead to vulnerability which can decrease autonomy, increase dependency and decrease illness management (Dashiff & Bartolucci, 2002). Conversely, for some adolescents, having a chronic illness can result in increased independence, increased illness management, which results in the development of autonomy. Ultimately, this can help in illness control. Chronic illness can increase autonomy issues because of strict treatment regimens, but relapse/remission can intensify emotions about loss or bring more dependency. Non adherence can be seen as an emotional issue of gaining independence and freedom (Dashiff & Bartolucci, 2002).

There is minimal literature on the development of autonomy in adolescents with chronic diseases. The research that does exist relates to Insulin Dependent Diabetes Mellitus (IDDM), learning disabilities, spina bifida, physical disabilities, and to determining compliance using autonomy in adolescents with juvenile rheumatoid arthritis (Dashiff & Bartolucci, 2002; Hostler,

Three of the studies found that autonomy was less developed or slowed in adolescents with chronic diseases compared to healthy adolescents (Litt, Cuskey & Rosenberg, 1982; Monsen, 1992; Murtaugh & Zetlin, 1990). One study found that there were no differences between autonomy development in adolescents with IDDM and healthy adolescents (Dashiff & Bartolucci, 2002). Further research is needed to assess these areas individually and over time.

Babies born HIV-positive in the early 1990s are now adolescents. Many have experienced delays in puberty due to the disease, although some have not (Buchacz, et al., 2003). More have experienced depression and anxiety not only from the disease, but also due to the loss of multiple family members from HIV (Levenson & Mellins, 1992). Others have specific cognitive deficits such as learning disabilities (Havens, & Mellins, 1996).

Adolescents who contracted HIV perinatally are vulnerable. They may have been isolated from their peers, may be forced to keep family secrets including their own HIV status, and may have undergone repeated hospitalizations. Others have been shuttled among foster homes and have not had the sustained care of a loving family (Smith-Rogers, 2006). These experiences make it difficult for an adolescent to reach autonomy as part of his/her development stage.

Review of the Literature

This review of literature addresses the concept of adherence as it has been researched through the literature. First, there is a definition of adherence, followed by the importance of adherence, studies done about the predictors of adherence among adolescents with chronic
disease, and the studies done about the interventions used to improve adherence among adolescents. A summary of the literature findings concludes this chapter.

**Definition of Adherence**

There is no gold standard definition of adherence. Adherence definitions address concepts such as behavior, correspondence with medical or health advice, following medical instructions, and active role of the patients in consenting to and corresponding with agreed recommendations (Chirag, 2007; Murphy, et al., 2005; Rapoff & Smith, 2005). Studies have demonstrated the lack of a standard definition of adherence. It is essential to define adherence clearly because the definition that is used can influence both the conduct of research and clinical management (Riekert & Drotar in Drotar, 2000).

For the purpose of this research, adherence is defined as “the extent to which a client’s behavior coincides with the prescribed health care regimen determined through a shared decision making process between the client and health care provider” (Frank & Miramontes, 1997). This definition focuses on adherence as a behavior, and emphasizes the importance of a patient’s active involvement in making decisions about his/her own care.

**Importance of Adherence**

The complexities of adherence can affect the results of treatment regimens. For example, high levels of medication adherence decrease complications and mortality associated with disease and delay disease progression. This improves quality of life for both the adolescent and his/her family (Chirag, 2007). Adherence is also important because of its impact on the ability of the medication to prevent complications and improve the disease. In order to make informed decisions about altering a treatment regimen, health care providers must know if a person is not
adhering adequately. Adhering to a regimen also reduces health care costs by minimizing visits to both doctors and hospitals (Frank & Miramontes, 1997). From the research perspective, information about adherence validates the quality of data collected from empirical studies. For example, poor adherence to a regimen can provide uncertain data on the efficacy of the particular regimen and or dosage (Tebbi, 1993; Matsui, 1997).

Treatment adherence is a significant issue for all people with chronic illnesses because non-adherence can lead to increased morbidity and mortality. There are many reasons why people do not adhere to their treatment regimens. Adolescence, however, adds an additional set of barriers because it is a time of rapid development and constant flux of peer pressure and the search for identity. For this reason, it is essential to seek a greater understanding of both the predictors of adherence in adolescents, as well as effective interventions for improving adherence.

*Predictors of Adherence Among Adolescents with Chronic Disease*

Research in the area of treatment adherence among chronically ill adolescents has helped clinicians and scientists begin to understand the complexity of the issue, identify adolescents at risk for non-adherence, and develop strategies to improve it. Predictors of adherence among chronically ill adolescents can be categorized into patient/family related, disease/regimen related and patient/provider related (Chirag, 2007).

*Patient/Family Related*

One of the most common predictors of adherence identified was patient or caregiver forgetfulness and remembering to take medications (Belzer, Fuchs, Luftman & Tucker, 1999; Byrne, Honig, Jurgrau, Heffernan, & Donahue, 2002; Van Es, et al., 1998; Waters, Radley-
Smith, & Sensky, 2006). In a descriptive study done with 42 families with a child or adolescent with HIV, the main aim was to identify the factors that influence medication adherence. Interviews were done in English or Spanish, and the patient’s charts and Visual Analogue Scales (VAS) were used in this study to collect data. Among the factors found that predicted adherence were taste, volume, forgetting, frequent dosing, and disclosure issues (Byrne, Honig, Jurgrau, Heffernan, & Donahue, 2002).

Adolescents who do not link taking medications with regular daily activities often have difficulties remembering to take their medications (Hosek, Harper, & Domanico, 2005; Murphy, et al., 2003). Forgetfulness can be related to a lack of routine. For example, medication that had to be taken in the morning was problematic for some adolescents because they were rushing to get to school. Similarly, holidays and other temporary life changes resulted in forgetfulness for some adolescents (Buston, & Wood, 2000).

Studies have demonstrated that adolescents with chronic diseases have higher rates of both emotional and behavioral problems (Smith & Shuchman, 2005). Research has also shown a link between mental health problems and poor levels of adherence (Ciesla & Roberts, 2001; Murphy, Wilson, Durako, Muenz, & Belzer, 2000). For example, depression, anxiety, denial, psychological distress, low self-esteem, and the use of illegal substances were significantly related with a failure to adhere (Hains, Berlin, Davies, Parton, & Alemzadeh, 2006; Murphy, et al., 2005; Naar-King, et al., 2006; Penza-Clyve, Mansell & McQuaid, 2004; Rao, Kekwaletswe, Hosek, Martinez & Rodriguez, 2007; Williams, et al., 2006).

In a qualitative study done with 25 HIV positive youth, ages between 17 and 25 years, the main objectives were to examine the attitudes that youth with HIV have towards the
antiretroviral therapy and to explore the barriers to medication adherence that they are faced with. Data was collected through focus groups. Among the findings were that 72% were drinking alcohol even when taking their medications for HIV. Side effects, alcohol/drug use and mental health issues were among the barriers that predicted adherence (Rao, Kekwaletswe, Hosek, Martinez & Rodriguez, 2007).

Depression can lead to non-adherence because of decreased energy, hopelessness or impairment in cognitive functioning, such as poor concentration (Smith & Shuchman, 2005). Mental health issues in chronically ill adolescents are often under-identified and therefore underrated (Neinstein, 2001). It is important to assess this populations’ emotional functioning, as well as their coping strategies, when making a treatment plan.

Family also plays an important role in adherence. Research indicates that family support, communication between family members, parental involvement (too much or too little), family dysfunction, stable living situation, strong and healthy parental relationship and living in an unsupportive or stressful atmosphere are determinants of adherence (Bikaako-Kajura, et al., 2006; Ellis, et al., 2007; Kyngas, 2000; Martínez, et al., 2000; Pugatch, Bennett, & Patterson, 2002; Zindani, Streetman, Streetman, & Nasr, 2006). In a quantitative study done with 42 HIV positive children and adolescents, aged 5 to 17 years old, and 42 caregivers, one of the main aims was to identify barriers that predicted adherence. Among the findings were that disclosure of HIV status to children by caregivers and strong family relationships predicted good adherence (Bikaako-Kajura, et al., 2006).

Families also play an important role in managing the disease (Lewin, et al., 2006). In a dysfunctional family where there is poor communication and too little support, adherence often
suffers because adolescents may be less likely to turn to their parents for support and joint
decision-making about adherence (Feinstein, et al., 2005; Lewandowski & Drotar, 2007;
Mackner, & Crandall, 2005, Miller, & Drotar, 2007). On the other hand, parental involvement
can also result in control struggles with the adolescent and increase the likelihood of non-
adherence. These struggles can be related to the desire of the adolescent to achieve autonomy. In
either case, it is necessary to include the family in discussions of ways to improve adherence.

Disease/Regimen Related

Adherence is often influenced by the characteristics of the disease or regimen. For example, disclosure and stigma were found to predict adherence in studies with HIV-positive adolescents (Bikaako-Kajura, et al., 2006; Byrne, Honig, Jurgrau, Hefferman, & Donahue, 2002; Gibb, et al., 2003). In a quantitative study done with 128 HIV positive children, aged between 3 months and 16 years old, and their caregivers, the main aim was to study adherence to a specific prescribed antiretroviral medication of PENTA 5 trial. Findings suggested that nelfinavir was reported to be the most difficult drug to take, but the difficulty decreased over time. Reasons for not taking the medications were related to taste, volume of drug, consistency of medications, and difficulty in swallowing (Gibb, et al., 2003).

Because of the stigma that still exists around HIV, HIV-positive adolescents preferred to keep their HIV status secret, which made it difficult to take medications in the presence of others (Abadia-Barrero, & Castro, 2006; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). Being rejected can isolate adolescents from their social support networks (Grubman, et al., 1995; Kissinger, et al., 1995). In an ethnographic study done with 50 children and adolescents with HIV and living in Brazil, aged 1 to 15 years old, the main objective was to describe the
experiences of stigma. Data were collected through unstructured interviews and participant observation. Findings suggested that stigma related to HIV happens within a complex discrimination process. Poverty, racism, inequalities in social status, gender, and age are all components of the stigma experience (Abadia-Barrero, & Castro, 2006).

Family members also faced issues of disclosure. Some of the reasons they gave for not giving medications were related to the fear of disclosure because the patient was out with friends or visiting relatives (Gibb, et al., 2003). Disclosure and stigma are important issues for chronically ill adolescents, and require further research.

Regimen complexity and length are other serious challenges for chronically ill adolescents (Giacomet, et al., 2003; Greening, Stoppelbein, Konishi, Jordan, & Moll, 2007; Martin, et al., 2007; Rosina, Crisp & Steinbeck, 2003; Veinot, et al., 2006). Patients on long-term or complex regimens are less adherent that those with shorter and simpler regimens (Fielding, & Duff, 2005). In a qualitative grounded theory research done with 34 HIV positive youths between 12-24 years old, the aim was to understand the HIV positive youth’s experiences and perceptions of HIV treatment. Some of the factors influencing adherence were fear of side effects, too much pills, confusion about how or when to take them, number of pills, prohibitive cost of treatment, and not believing in the value of treatment (Veinot, et al., 2006).

The complexity of a regimen is influenced by number of pills, number of doses daily, instructions on how they are to be taken, and schedule. A treatment regimen can affect an adolescent’s job, school or activities outside the house (Pugatch, et al., 2002). Some adolescents felt that instructions on how to take the pills and the schedule were too strict, interfered with their lifestyle or disrupted their social routines (Belzer, et al., 1999; Goode, McMaugh, Crisp, &
Wales, 2003; Van Dyke, et al., 2002; Veinot, et al., 2006). Characteristics of the pills such as size, taste, smell and side effects can also interfere with adherence (Hosek, Harper, & Domanico, 2005; Rosina, Crisp & Steinbeck, 2003). The number of pills and the administration schedule of a regimen can both influence adherence (Giacomet, et al., 2003; & Goode, McMaugh, Crisp, & Wales, 2003).

Additional predictors related to the disease include physiological markers such as CD4 count, viral load, and Hb A1c. These physiological markers were associated with other measures of adherence, such as self-report, to predict adherence (Feinstein, et al., 2005; Gilkman, Walsh, Valkenburg, Mangat, & Marcinak, 2007; Martin, et al., 2007; Patino, Sanchez, Eidson, Delamater, 2005; Rongkavilit, et al., 2007).

Patient/Provider Relationship

A variety of studies have shown the importance of both the patient/provider relationship and patient/provider communication on achieving adequate adherence among adolescents with chronic illnesses (Kyngas, 2000; Kyngas, Hentinen, & Barlow, 1998; Pugatch, Bennett, & Patterson, 2002). These studies all reported that supportive and effective communication was important for helping adolescents understand their disease and treatment, and for improving self-efficacy. In a qualitative, grounded theory study done with six (6) adolescents with HIV aged 16 to 24 years old, the main objective was to identify the major factors that correlate with HIV positive adolescent adherence to drug regimens. Findings suggested that among the factors that negatively affect adherence, besides fear of social stigma relating to HIV disclosure, was the quality of the doctor-patient relationship (Pugatch, Bennett, & Patterson, 2002).
Interventions Used to Improve Adherence Among Adolescents

Interventions designed to improve adherence among adolescents often focus on the predictors of adherence. Patient/family interventions were designed to improve relationships, problem solving strategies, behaviors, decision-making skills, support, mental health issues, communication, knowledge of disease and regimen, and adherence skills. The disease/regimen interventions were designed to improve and simplify schedules, tailor regimens to fit the adolescent’s and family’s lifestyles, improve knowledge of regimen, provide reminders, and manage side effects. The patient/health care provider interventions were designed to improve confidence, relationships, communication, support, and collaboration.

Some programs take a multidisciplinary approach. These include programs such as the Therapeutic Regimens Enhancing Adherence in Teens (TREAT) (Smith-Rogers, Miller, Murphy, Tanney, & Fortune, 2001) and the Boston HIV Adolescent Provider and Peer Education Network for Services (HAPPENS) Program (Woods, et al., 2004), both of which offer comprehensive medical and psychosocial services including peer education, counseling, group support and case management. They require intensive participation by the adolescents and/or the families and integrate a comprehensive continuum of care (Smith-Rogers, Miller, Murphy, Tanney, & Fortune, 2001; Woods, et al., 2004).

Multisystemic therapy (MST) is designed to work with the adolescent, the family, the community, or some combination of the three. For example, one study of an office-based intervention for diabetes medication adherence provided a teamwork intervention for adolescents and their parents to one study group, attention control to another group and standard care to another group. The study reiterated the importance of the parent involvement in managing the
adolescent’s disease (Anderson, Brackett, Ho, & Laffel, 1999). In one home-based MST intervention, one group of families received psychotherapy and standard care while another received only standard care (Ellis, et al., 2005). The intervention techniques included cognitive behavioral therapy, parent training and behavioral family system therapy. The group that received psychotherapy and standard medical care adhered better than the group that received standard medical care (Ellis, et al., 2005). Other MST interventions have variously provided weekly support to HIV-positive adolescents and their caregivers (Ledlie, 2001), education and support to HIV-positive adolescents and their families (Berrien, Salazar, Reynolds, McKay, & HIV Medication Adherence Intervention Group, 2004), and hospital-based interventions using directly observed therapy (Parsons, et al., 2006).

Another home-based intervention program for adolescents and parents focused on improving adherence by increasing knowledge and individual goal setting in adolescents with IDDM (Couper, Taylor, Fotheringham, & Sawyer, 1999). The six-month intervention was provided by a diabetes nurse educator, and was effective in improving adherence. Twelve months later, however, the benefits were not maintained, demonstrating the need for regular follow up to maintain adherence (Couper, Taylor, Fotheringham, & Sawyer, 1999).

Another study used behavioral family systems therapy for diabetes (BFST-D), and focused on interventions to improve family relationships and adherence to diabetes specific behavioral components (Wysocki, et al., 2006). The BFST-D consisted of cognitive restructuring, training in problem solving and communication, and functional-structural family therapy.

A motivational intervention model for adolescents in the Dietary Intervention Study in
Children (DISC) offers strategies for increasing adolescents’ readiness to change health behaviors and improve dietary adherence (Berg-Smith, et al., 1999). The program provides an assessment of readiness to change and then intervention strategies tailored to the participant’s position on the readiness to change continuum. This intervention was acceptable for the adolescents and appeared to be an age appropriate intervention (Berg-Smith, et al., 1999).

Two other studies reported on modern-day adherence interventions (Franklin, Waller, Pagliari, & Greene, 2006; Puccio, et al., 2006). Both interventions used cell phone reminders calls and text messaging – “sweet talks” – to provider reminders and support.

The findings of the empirical studies suggest that there is no standard intervention to address the problem of treatment adherence. No single strategy or program is effective for everyone, but a combination of cognitive and behavioral interventions has been found to be more effective than single interventions. Also, including the adolescent with the family and the community is more beneficial in improving adherence, although these programs are more expensive for the clinic and more intensive and time consuming for the participants. Further research is needed to explore the benefits of combining interventions.

Summary and Conclusion

This review of literature has provided an important base of knowledge related to adherence among adolescents with HIV. It has also highlighted the lack of research on adherence from another cultural perspective, besides the USA culture and from the experiences and meaning of adherence to chronically ill adolescents. More research is needed to explore the applicability of the existing knowledge to other cultures and to create a body of knowledge that embraces new settings and cultural contexts for medication adherence.
Other issues and gaps have been identified that will also inform my research. First, there is no standard conceptual definition of adherence. It is necessary to have a clear, generally accepted definition, as this is the main concept being studied. That definition will influence the conduct of the research and guide clinical management (Riekert & Drotar in Drotar, 2000).

There is also no standard operational definition of adherence. Relatively few studies explicitly defined adherence in operational terms. Some used categorical definitions such as, “no missed or reduced doses” during a given time period. Others used “more than 95%” for good adherence (Katko, Johnson, Fowler, & Turner, 2001; Van Dyke, et al., 2002).

To date, adherence has been studied mostly using cross-sectional methodologies. Although this has provided important information about predictors, longitudinal data could provide further evidence regarding patterns of adherence over time and long-term predictors as well as providing more data about the importance of follow up.

Qualitative research on adherence in adolescents is also lacking. Qualitative methods can help to describe and increase our understanding of the behaviors that predict medication adherence. They can also increase our understanding of perceptions, experiences, and meanings that are important in adherence, as well as the social and cultural dimensions. Use of qualitative methods will provide important information in theory development for specific populations.

There is also a need for more research on the relationships between adherence behaviors and the developmental aspects of adolescence. Only one study has identified age as a predictor of adherence (Murphy, et al., 2005). Although a number of studies mentioned adolescence as an issue in passing, there was no actual research on the topic. Studying the adolescent from a developmental perspective will add new knowledge about adherence among adolescents.
Finally, the use of mixed developmental stage populations to assess adherence can provide for very important data to be lost because of the complexity/heterogeneity of the population used. Very few studies included only adolescents – most included a combination of patients with chronic diseases, from toddlers to children to adolescents. Research focused specifically on adolescents is necessary to gain a greater understanding of the issues they face.
CHAPTER THREE: METHODOLOGY

This chapter provides a description of the research design used to investigate the basic social processes of medication adherence in Puerto Rican youth who are HIV positive. This chapter also discusses Strauss and Corbin’s grounded theory as the methodology for this research. This is followed by a description of the sample size with inclusion and exclusion criteria, how participants were recruited, a description of the setting where data was collected, and the procedures used to protect human subject’s rights. Finally this chapter concludes with a description of how the data were collected, data analysis procedures, how trustworthiness was established and a summary.

Grounded Theory

The purpose of this study was to describe the basic social processes of medication adherence in Puerto Rican youth who are HIV positive. Grounded theory is a methodology that offers a way of thinking about and studying social reality (Strauss & Corbin, 1998; Wuest, 2007). This methodology evolved within the social sciences and explores social processes present in the human interaction. The phenomenon of social reality to be studied is medication adherence. Because adherence is a behavior that depends on the social interaction, grounded theory is an excellent fit to answer the research question for this study.

The theoretical foundation for GT is in symbolic interactionism (SI) is a socio-psychological theory of social action designed to yield verifiable knowledge of human group life and human behavior (Blumer, 1969). SI is a theory of human conduct focused on the relation between the human beings and their social environment. SI posits that people behave and interact based on how they interpret and give meaning to the symbols in their lives (Wuest, 2007). In
other words, human beings act/behave toward objects according to the meanings they attribute to those objects as a result of previous social interactions (Blumer, 1969). Adherence to a prescribed medicine regimen is a behavior derived from social interaction and the meanings attributed to the medications and interactions. It is expected that this GT research will generate a substantive theory describing the basic social processes of medication adherence by Puerto Rican youth who are HIV-positive.

Grounded Theory According to Strauss and Corbin

Strauss and Corbin present grounded theory as a qualitative research method that uses a systematic set of procedures to generate a theory about a phenomenon based on the data collected and analyzed (Strauss & Corbin, 1990; Strauss & Corbin, 1998). The origin of Strauss and Corbin’s grounded theory methodology rests on the following ideas: the need to understand the complexity of a phenomenon; the importance of the theory developed under a basis of social action; the active role of the subjects being studied; realizing that the subjects have their own interpretative meaning of a phenomenon and that this meaning can change through interactions with other subjects; and having sensitivity to what can be discovered about the phenomenon (Strauss & Corbin, 1998).

GT is conducted through constant comparative analysis. That is, the final theory arises from continually collecting, analyzing and comparing data in an iterative and interactive fashion. The data arises from the reality of the subjects being studied. The substantive theory will consist of concepts that reflect patterns of action and interaction between and among the participants in this study.
Grounded theory has three basic elements: concepts, categories and propositions. Concepts are the basic units of analysis since it is from the conceptualization of data, not the actual data per se, that theory is developed (Strauss & Corbin, 1998). Categories are higher level and more abstract than concepts. They are generated through the same analytic process of comparison, to highlight similarities and contrasts and thus uncover differences, that is used to produce lower level concepts. They provide the means by which the theory can be integrated. Propositions indicate generalized relationships between a category and its concepts and between discrete categories (Strauss & Corbin, 1998).

Components of Grounded Theory According to Strauss and Corbin

*Research Questions*

Research questions from a GT study must be related to basic social processes (Strauss & Corbin, 1998). The research questions for this study are: 1) What are the basic social processes of medication adherence in Puerto Rican youth who are HIV- positive?; 2) What factors influence medication adherence (or nonadherence) among HIV- positive adolescents?; 3) What behaviors indicate that the HIV- positive adolescents adhere or do not adhere to their prescribed medications?

*Review of the Literature*

The review of the literature when doing a GT research is an issue of discussion. Glaser prefers to do this review after data have been collected and in the process of being coded. This will avoid falling prey to preconceived ideas (Glaser, 1992). The review of the literature should be used as another source of data, to be used in the constant comparative analysis process when the data is being categorized (Glaser, 1992).
On the other hand, Strauss and Corbin (1998) believe that reviewing the literature in the beginning of a research process is necessary in order to identify a specific research question. This may include nontechnical literature (Strauss & Corbin, 1998). For example there are concepts from the literature that can help in the process of analyzing the data. They can help establish similarities and/or differences. It is expected that the researcher will be aware that reviewing the literature can decrease the creativity related to GT methodology (Strauss & Corbin, 1998; Wuest, 2007). Another point is that previous review of the literature can help create more questions during the process of analyzing the data (Strauss & Corbin, 1998). In keeping with Strauss and Corbin’s methods, the present researcher conducted a literature review (as seen in chapter two) in preparation for conducting this GT study.

**Theoretical Sampling**

Theoretical sampling is part of this qualitative methodology. It is defined as a way of sampling that depends on the richness and analysis of the data collected (Strauss & Corbin, 1998; Wuest, 2007). The goal is to sample incidents rather than participants and to collect data that will help strengthen the categories previously identified and provide a better understanding of the phenomena under study. Depending on the data that have been analyzed, compared, and contrasted further/new questions are identified that will require the continued recruitment of more participants. As more data are collected this will add to the previous data collected and analyzed and will strengthen the identification of categories. As can be seen the process of sampling and analyzing has to be done sequentially (Strauss & Corbin, 1998). Questions such as “What would happen if…?; When?; How?; and Where?, are important to be answered during the
process of data analysis because they are the basis for the sampling process (Strauss & Corbin, 1998).

Wuest (2007) recommended a sample size of approximately 40 individuals, for a GT study. However, the actual number of participants in a GT study will depend on the richness of the data collected, the progress of analysis with respect to categories identified and will finally depend on the development of a substantive theory related to the phenomenon studied (Wuest, 2007).

**Theoretical Sensitivity**

Theoretical sensitivity is related to theoretical sampling because the more sensitive the researcher is to the concepts and categories identified, the more he/she will search for data to reinforce those concepts and categories identified. It is expected that the researcher will have the ability to recognize what it is important in the data and to find meaning in it (Strauss & Corbin, 1998; Wuest, 2007). The personal characteristics of the researcher are important for theoretical sensitivity, which comes from personal and professional life experience, as well as immersion in the literature and the analytic experience itself. Prior to this study, the researcher had extensive professional experience with the study population through work as a nurse. Personally, she was the mother of an adolescent herself. Attempting to answer the “Why?”, “When?”, “How?”, “Where?” and “What would happen if…?” questions about the data collected can guide the researcher to theoretical sensitivity (Strauss & Corbin, 1998).

**Data Collection**

In qualitative research data are collected using various techniques, such as participant observation, semi-structured interviewing, field notes, memos, documents, reports, diaries (Noll-
Hoskins & Mariano, 2004). For the purpose of this research, data were collected using observations, in-depth interviewing, field notes, and memos.

Observations included the observation of the participant’s non verbal communication and responses to the researcher. Semi-structured interviews are conversations for the purpose of providing data of the phenomenon under study. These interviews include open questions that are intended to provoke a narrative about the participant’s feelings and viewpoints (Noll-Hoskins & Mariano, 2004). Interviews were transcribed for the purpose of analyzing them after each interview. Field notes are written data collected in the setting that contains various bits of information important and to be noted and used during the process of data analysis (Noll-Hoskins, & Mariano, 2004). Memos are part of the grounded theory methodology. They are records of how the data were collected and analyzed. Memos can be used as reminders and sources of information and further direction for the researcher. These memos included information about how the coding was done and how the categories were initially identified (Strauss & Corbin, 1998; Wuest, 2007).

**Data Analysis**

Data were analyzed using the constant comparative method in all the coding procedures and terminated when theoretical saturation was achieved. Theoretical saturation happened when no new or relevant data emerged from the interviews and categories; also when the categories were well developed in terms of their properties and dimensions demonstrating variation; and when the relationships among the categories were well established and validated. When no new data and information emerge during the identification of codes saturation is reached (Strauss & Corbin, 1998).
In constant comparative analysis, new data are compared with other previous data collected for similarities, differences, and to aid in categorizing data into groups (Strauss & Corbin, 1998). At the end of this process, a substantive theory of the phenomenon develops. When comparing categories, it is called theoretical comparisons (Strauss & Corbin, 1998).

For Strauss and Corbin, the way in which data are organized according to their properties and descriptions is important for identifying the categories that will be used in developing the theory (Strauss and Corbin, 1998). There are three coding procedures in this approach: open coding, in which the data are broken down, examined, compared, conceptualized and categorized; axial coding, in which the data are connected by identifying categories and subcategories; and selective coding, in which core categories or central phenomena are identified, relationships are validated and categories are linked in order to theorize (Strauss and Corbin, 1998).

*Grounded Theory Used in Adolescent Research*

Grounded theory methodology has been used in research about adolescents and in research about medication adherence, but not about medication adherence in adolescents who are HIV positive. In the research about adolescents, concepts such as pain, depression, sexual behaviors, hopefulness, stigmatization, suicide, and illness, and in different chronic diseases have been studied using grounded theory (Crandall, Kools, Miaskowski, & Savedra, 2007; Gratton & Bouchard, 2001; Hinds & Martin, 1988; ; Reichenberg, Lindfred, & Saalman, 2007; Rich, Taylor, & Chalfen, 2000; Sherman, et al., 2008; Whitley & Kirmayer, 2008). Grounded theory also has been used as the methodology when studying different issues concerning HIV and adolescents. Concepts such as HIV risk, systemic inequities, sexuality, and disclosure are some
of the concepts that have been studied using grounded theory (Christianson, Lalos, Westman, & Johansson, 2007; Larkin, et al., 2007; Ledlie, 1999).

Concerning the specific research topic, medication adherence in adolescents with HIV, the literature presented one study done in 2002 (Pugatch, Bennett, & Patterson, 2002). The major aim of the study was to identify major factors which may correlates with HIV positive adolescent adherence to drug regimens. Six (6) adolescents with HIV, aged 16 to 24 years old, were the participants in the study. Using unstructured interviews the factors that emerged as negatively affecting medication adherence, in this population, were: a strong fear of social stigma relating to HIV disclosure; familial over involvement in the regimen; the fact that it is a complex drug regimen; medication side effects; poor general knowledge about HIV infection; and the quality of the doctor-patient relationship. According to this research, further studies are needed to elucidate HIV medication adherence among this population in order to improve their treatment outcomes (Pugatch, Bennett, & Patterson, 2002).

Protection of Human Rights

Approval for this study was granted by the Human Subjects Protection Committee of the University of Arizona (Appendix A) and the University of Puerto Rico, Medical Sciences Campus (Appendix B). Letter of approval and collaborative agreement between the clinical site, GAMMA Immunology Clinics and the researcher were obtained to conduct research and recruit participants for this study (Appendix C). Informed consent forms given to the participants and their legal guardians were also included in the submission of the research to the IRB (Appendix D through J). Protection of privacy and confidentiality was addressed by giving each participant a pseudonym for use in the interview. No real name was used during the interviews. Transcripts
of the interviews were locked in a file to which only the researcher had the key. Demographic instruments were coded to also assure the privacy and confidentiality of the participants.

Sample Size

Using theoretical sampling and identifying the most appropriate participants, one can increase the depth of the data collected and the quality of it. Theoretical sampling determined inclusion criteria for studying participants: HIV- positive, aged between 15 and 19 years old, female or male, able to speak Spanish or English, receiving antiretroviral medication and can understand the questions and reply unassisted. Exclusion criteria were: younger than 15 years old and older than 19 years old, not able to understand the questions, not fluent in either English or Spanish, diagnosed with any condition that precluded participating in an interview, and receiving no treatment for HIV/AIDS.

The sample size for this research was determined by saturation that is when the data collected start to become repetitive new or relevant data emerged from the interviews; when the codes and categories were well developed in terms of their properties and dimensions. The precise or exact number of subjects to be used when using this methodology cannot be planned. It evolves during the research process (Strauss & Corbin, 1998). It was essential that the investigator interviewed enough Puerto Rican HIV - positive adolescents so that a clear picture of the experiences that determine whether this population adheres to their medications, or not, was obtained. For this research, a purposive sample size of 13 Puerto Rican HIV-positive adolescents was used.
Setting

Puerto Rican HIV - positive adolescents were selected from the GAMMA Immunology Clinic located in San Juan, PR. The GAMMA Immunology Clinic started in 1988 as a research study project in HIV-positive children. Because by that time the HIV-positive children population increased, it was necessary to integrate the component of health care services. On March, 1992 The GAMMA Project turned to be an AIDS Clinical Trail Unit (ACTU) or the Pediatric Unit of Clinical Studies in AIDS. In the present the clinic is known by the GAMMA Immunology Clinic.

The purpose of ACTU is to provide research regarding the treatment for HIV to infants, children and adolescents. The clinic is part of the University of Puerto Rico, Medical Sciences Campus. It receives federal funding from the National Institute of Health (NIH) and the National Institute of Allergy and Infectious Diseases, Division of AIDS (NIAID-DAIDS). Their main objective is to provide research, education, treatment and comprehensive services to HIV-positive children and adolescents in order to maximize a better quality of life.

Services provided include: medical evaluation, research, treatment, vaccination, laboratory, education, counseling, pharmacy and social evaluation and follow-up. In the beginning, the medical services were available to HIV-positive children and adolescents that lived in the health Metropolitan region that include the towns of Canóvanas, Carolina, Guaynabo, Loíza and Trujillo Alto. As for today this medical care is provided to any HIV-positive children or adolescents from any part of the island. Participation in the research studies are completely voluntary and will depend upon the criteria establishes. Some of the personnel
that work in the clinic are: medical director, coordinator, administrator, pediatricians, social worker, pharmacist, psychologist, nurses, data management, nutritionist and others.

As for today, the clinic offers their services to 80 children and adolescents HIV-positive. Among those, 74 have more than 13 years old and 6 have 12 years old or younger. Over 95% of the children and adolescents that assist to this clinic were perinatally infected by the HIV virus. Also the clinic has more or less 200 children HIV–negative and 12 infants 6 months or younger not yet diagnosed.

Recruitment of Participants

After obtaining all the approval letters, including those granted from the Human Subjects Protection Committee of the University of Arizona and the University of Puerto Rico, Medical Sciences Campus, a meeting was conducted with the health care providers (HCP) regarding study protocols and subject recruitment. The social worker of the GAMMA Clinic provided the researcher with the phone numbers of the potential participants and according to the appointment scheduled. Each potential participant was phoned and asked for their willingness to participate when they came to their appointment. Also, the legal guardian of the potential participant was informed about the research and their willingness to let the adolescent participate; they were also informed that they should come to the appointment in order to sign the consent form that allows the adolescent to participate.

When a potential participant arrived at the clinic the researcher met him/her and reminded him/her about the research and asked to talk with him/her after the appointment was finished. The adolescent (and his/her parent, or legal guardian, if s/he was a minor) was invited to read the consent form and the researcher answered any questions. If the individual (and
parent/guardian, if appropriate) decided to participate, signatures were obtained on the consent form. If the youth with HIV was age 18 or older, could consent for him/herself.

**Data Collection Procedures**

After the participant finished the appointment at the GAMMA Clinic, the researcher met the participant and the legal guardian and asked again for the willingness to participate. Consent form was explained to the participant and legal guardian, questions and doubts were answer before both signed the consent form.

After the signing, data collection started. Each participant chose a pseudonym for the interview before beginning the interview. Semi-structured interviews were used to collect initial data. These semi-structured interviews were audio taped. Field notes and memos were used. An instrument was used to collect demographic data from the participants. Other source for data collection was the review of the literature. The process of data analysis of each interview was completed before conducting the next interview.

**Instrument**

Data gathered with the demographic instrument included: date of interview, code number, age, gender, marital status, highest grade completed, residence, with whom the participant lives, age at being diagnosed and “age that you knew that you had HIV” (Appendix K). Examples of questions that were used during the semi-structured interview are in Appendix L (Spanish Version) and Appendix M (English Version).

**Data Analysis Procedures**

The basic social processes (BSP) of medication adherence in HIV-positive adolescents were generated from the analysis of the interviews. Analysis of each interview was completed
before conducting the next interview. Each interview was transcribed verbatim, in Spanish.

Before analyzing the interview, the researcher reviewed each transcription while listening to the audiocassette to ensure accuracy of the transcription. Data analysis included reading the interviews and searching for consistencies, reviewing field notes and reflecting on observations made during the interviews. Field notes included data regarding, among other things, a description of the setting where the interview took place, a physical description of the HIV-positive adolescent, nonverbal communication by the participant, and the researcher’s feelings during the interview. After the interview was finished, further field notes including the researcher’s afterthoughts about the interview, things to remember for the next interview, and analysis of “what went on” during the interview, were immediately written down.

Analysis and interpretation of transcription and field notes were done line-by line or paragraph by paragraph, allowing for the identification of categories. Each category was defined and described according to the participants. The identification of sub-categories helped summarize and clarify each category.

After categories were identified, the process of theoretical comparison was done in order to analyze similarities and differences among categories identified. This process led to the identification of open coding. Open coding identifies concepts and defines the properties (characteristics) contained in the data collected from the interview (Corbin & Strauss, 2008). Memos were done as part of the process of identifying the open coding. Memos contain the open coding with their properties and descriptions, the researcher’s analysis and literature review. The literature helped in the process of making comparisons, defining categories and identifying questions to ask in the next interviews to explore an identifying code. The memos helped in the
identification of more categories and sub-categories. This analytic process, although it was done with each interview and the next interview was not done until the previous analysis was complete; the researcher went back to previous interviews and analysis when a new category or code emerged from another new interview.

As the analytic process continued, more questions arose whose answers helped in the analysis and throughout the next interviews. Axial coding emerged as the previous categories were identified and comparisons were done as an iterative process. More memos were written where the conceptual process of identifying and comparing open and axial codes (backward and forward process) were described. Memos helped in the identification of saturation of an identified category. By this time most categories were integrated into major categories (selective coding). In the process of analysis the researcher was able to identify and integrate these into the central category identified as “the BSP of medication adherence in Puerto Rican youth who are HIV-positive.” At the end, a diagram was constructed in order to visualize how the major categories are related to the central category. The diagram is also a visual frame of reference for the BSP of medication adherence.

Trustworthiness

A variety of methods exist for ensuring trustworthiness in qualitative research. Because in grounded theory the researcher attempts to understand a phenomenon through the experiences of the subjects, in their natural settings, as they lived it and perceived them, the criteria to establish trustworthiness according to Lincoln and Guba will be the ones used in this research. Constructionists believe in subjectivism as the epistemology, in multiple realities and
perspectives (there is no one truth) as the ontology, and in the naturalistic methodologies. Because of this Lincoln and Guba’s criteria of trustworthiness fits this paradigm.

According to Lincoln and Guba, trustworthiness involves credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). For the purpose of this research credibility and dependability were used to establish trustworthiness.

Credibility

Credibility occurs when a research subject identifies the truth of the findings within their own social context. This means that the research findings are compatible with the perceptions of the subjects being studied.

A variety of methods, such as prolonged engagement, member checking and peer debriefing among others, were used to ensure trustworthiness in this study. Credibility was established through prolonged engagement, which helped the researcher’s trust by, and credibility with the PRHPA. The researcher spent time working in the immunology clinic where the participants go for health care.

*Peer debriefing* was another method used to enhance credibility. For peer debriefing, a professor of the University of Puerto Rico, Medical Science Campus, School of Nursing with a Doctorate in Science of Nursing and with more than ten years working and doing research with patients with HIV, was in charge of this process. The process involved sending her the first two transcripts, in order for her to read and identify categories. A meeting was held, where the researcher identified the categories and was discussed and compared with the peer. This provided to the researcher not only a comparison of findings but also the development of new ideas about the data analysis. This exposed the researcher to questions from this peer who have had
experienced in qualitative methodology in research where HIV-positive persons have participated. It also exposed the researcher with guidance on the process of constant comparison of data.

Besides the meeting, although it was not planned previously, this professor also provided assistance to the researcher by telephone, with discussion of more codes identified, the development of categories, and the presentation of the diagram of the BSP that emerged from the data analysis. Areas to be improved regarding the analysis were discussed. Some of the areas to improved were the use of the literature for identifying categories.

This peer debriefing process also served to stimulate the student researcher’s reflexive process. Some questions raised to the student researcher by the person who participated as the peer debriefed were: What do you mean by…? What is important about this to you? Can you describe or named the properties of that category? How that does relate this to…? Why do you think this is happening? And explain to me, how you got to this.

Although it was not planned initially, as the study advanced, the researcher wanted to strengthen trustworthiness of the findings. Member checking was the method chosen for this process.

Member checking also contributed to credibility by validating the findings with some of the participants. This was done when interviewing 3 PRHPA that participated in this study. Some questions were asked to the participants about the emerging data, and the interpretations of those data. Codes and categories that emerged from the analysis were explained to the PRHPA in order to receive feedback about how these codes and categories fit their experience. The participants had the opportunity to react to those questions and express their own concerns and experiences
about the findings. They all agreed in that all started the moment they knew that they had HIV. Also that facing the diagnosis was an everyday experience and part of their daily living about what it is or what it means to have HIV. Living with HIV was about using ways of dealing daily with HIV. When it was presented the category of taking the pills, they agreed that some PRHPA talk about their pills and others about the pills. After going back to the transcribed interviews, this was identified and the category was modified.

Dependability

Also as it happened with member checking, dependability was another method used to established trustworthiness. Reflexivity and establishing an audit trail were used to enhance dependability. Reflexivity consisted of writing the researcher’s feelings before, during and after the interviews. These field notes were analyzed after analyzing each of the transcriptions.

The audit trail was created by noting how codes, categories and themes were identified through the analysis process. Also, how the relationship between the categories and emerged themes were established as part of the audit trail. A notebook was used for this purpose. A format was created where the raw data were written in a column and the codes in another column. After this was done on each interview, another format was created where the codes were written and categories were identified. These formats helped organize and document the sources of the data. It also helped in proving the accuracy and legitimacy of the analysis process.

Also when writing the results of the analysis and after making some changes, I saved the old one in a word file in order to keep an audit trail. Immediate ideas and all the processes and strategies used to made decisions were also kept in the notebook. Keeping this evidence provides for the auditor an order to follow of how decisions were made.
Establishing trustworthiness using a variety of techniques helps enhance the integrity of a qualitative research study. It should be done throughout the entire research process because it will help identify problems in the process of performing the study.

Summary

This chapter presented grounded theory as the methodology selected for conducting this research. Protection of human rights, the IRB process, along with the sample size, setting and recruitment of participants were described in this chapter. The chapter ended with a discussion of how the data was collected and analyzed, and how trustworthiness was evaluated.
CHAPTER FOUR: RESULTS

Introduction

The purpose of this research was to describe the basic social processes (BSP) of medication adherence in Puerto Rican youth who are HIV positive. Three research questions were proposed: What are the basic social processes of medication adherence in Puerto Rican youth who are HIV positive? What factors influence medication adherence (or nonadherence) among HIV positive adolescents? What behaviors indicate that the HIV positive adolescents adhere or do not adhere to their prescribed medications?

In this chapter, the sample is first identified, including a description of each participant, followed by various tables that describe the demographics and other characteristics of the participants, including their treatment regimen. The substantive grounded theory emerging from the data analysis is presented; with the basic social process of Striving to Live a Normal Life.

Sample

Brief Presentation of Each Puerto Rican HIV Positive Adolescent Participant

As in all studies were confidentiality has to be preserve, for this research, pseudonymous names were used in all participants.

Alejandro

Alejandro is an 18-year-old male who is attending the University of Puerto Rico with an interest in music. Alejandro lives with his aunt, who is his legal guardian, and her children. The day of the interview he came well dressed. Alejandro had taken complete responsibility for his treatment regimen, including attending his appointments by himself and locating and taking his
antiretroviral (ARV) medications when he was 16. He has a girlfriend, and they are expecting a baby.

Benicíó

Benicíó is a 19-year-old male. Both parents died of AIDS. His legal guardian is his grandmother, who was diagnosed with a chronic disease a few years ago. At the time of the interview, Benicíó had finished high school and was hoping to find a job and start college once he was recovered from his last hospitalization. Benicíó is totally responsible for his treatment including getting to the clinic and getting his ARV medications. He has had multiple hospitalizations and because of this and his physical symptoms, Benicíó is very sick.

Camila

Camila is a 19-year-old female. She lives with her father. Her mother died of AIDS when she was in elementary school. She finished high school and at the moment she works in an office.

David

David is a 16-year-old male. He is in high school and lives with his cousin and grandmother. Although his mother is alive, his grandmother is his legal guardian. David’s interview was difficult because he did not understand some of the questions. As with Benicio’s interview, more questions had to be asked in order to have complete answers.

Estefany

Estefany is a 16-year-old female. She was in high school and lives with her mother, grandmother and two siblings. Although she lives with her mother, her grandmother is her legal
guardian. Estefany was sick recently, and was hospitalized, causing her to miss a substantial amount of time from school.

**Gladys**

Gladys is a 16-year-old female. She is in high school and lives with her grandparents. She knew her HIV status at the age of 12 when asking her grandfather about all the medications she had to take every day.

**Hilda**

Hilda is a 16-year-old female. She is in high school and lives with her mother, grandmother and brother. She knew her HIV status at the age of 14 by her mother. She has not disclosed her HIV status to anyone else because she is afraid of being rejected.

**José**

José is a 15-year-old male. He is in high school and lives with his father and stepmother. He does not talk that much so more questions had to be asked. When he was 9 years old, he was told that he had HIV at the clinic by the social worker and his father.

**Keisha**

Keisha is an 18-year-old female. She lives with her mother and sister. She is attending her first year at the University. She was told that she had HIV when she was 16, but she already knew it because she had read a letter that came to her house about her disease. Although she knew, she kept it a secret until her mother told her.

**Lya**

Lya is a 15-year-old female. She is in high school and lives with her adopted mother, aunt and cousin. At the age of 6 the process of disclosure started. By the age she of 8 her mother and
physician had told her that she was HIV positive and that was why she was taking the pills and had to go to the clinic.

Zaida

Zaida is a 17-year-old female. She is in high school and lives with her father, stepmother, step-grandmother, her sister-in-law and her sister-in-law’s daughter. She was told that she had HIV when she was 15 years old. She felt upset, frustrated, mad and sad. Later she felt depressed because she knew that HIV was not an easy disease.

Maria

Maria is a 19 year old female. She finished high school and is attending her first year of university. Maria lost both parents of AIDS. She lives with her grandparents. By the age of 8, Maria was told about her HIV status by the healthcare provider. Her HIV status was disclosed to her by telling her a story that the healthcare provider was reading to her. She remembered that it was a cartoon story book.

Ninoshka

Ninoshka is a 19 year old female. She lives with her grandmother. She is in high school, but not a regular high school but in an alternative school. At the age of 12 her psychologist disclosed her HIV status to her. She was with some nurses, her uncle, grandmother and brother when she was disclosed. There were also paramedics in the room just in case she felt emotional distress so bad that she need it attention. After being told about her HIV, her grandmother needed attention because she started to cry uncontrollably. Ninoshka explained that her grandmother kept the secret of her HIV status for so long that when she knew, she felt relieved.
Characteristics of the Participants

A total of 13 Puerto Rican HIV positive adolescents (PRHPA) participated in this study. All were perinatally infected by the HIV virus. Nine (69%) of the participants were female and four (31%) were male. Most of the participants 8 (62%) were 16 years old and 19 years old. The mean age was 17.1 years. Nine (69%) of the 13 participants live in the northern area of PR and 10 (77%) in the urban zone. Ninety-two percent (12) are students and of those 62% (8) are in high school. Slightly more than half (7 = 54%) live with their grandmother and four (31%) live with their mother. Between the ages of 4 and 16 years the process of disclosure started for these adolescents. None of them have been informed of having AIDS. Most of them, 62% (8) have been on ARV medications for more than 15 years.

Most of the participants have lost one or both of their parents because of AIDS. Three (23%) of those adolescents, have lost a father, five (38%) have lost a mother, and four (31%) have lost both parents. Only one participant still has two living parents but they do not live together. Although most have lost at least one parent, six (46%) have at least one grandparent as their legal guardian and five (38%) have at least, one of their biological parent. Only one was adopted.

Regarding their ARV medications, Viracept was the protease inhibitor of most common (5=38%) used in the treatment regimen of these participants. Of the nucleoside transcriptase inhibitors (NRTIs), the most common ones used by these participants are Zerit (9 = 69%) and Epivir (5 = 38%). In addition, besides taking ARV medications, five (38%) of the participants also take antibiotics. These PRHPA take between three and nine pills daily. Four (31%) take five
pills daily and two (15%) take seven pills daily. This treatment is divided into taking doses every 12 hours.

Introducing the Basic Social Process: Striving to Live a Normal Life

The BSP that emerged after the process of constant comparison of the data was *Striving to Live a Normal Life* (Figure 2). The core category that emerged through all the interviews was the concept of *normal*. This BSP linked the relationship between the identifying codes, and categories in order to provide a description and understanding of how each HIV-positive adolescent adheres to their ARV medications. This process of *Striving to live a normal life* with the core category of *normal*, defined and described how this PRHPA learned about their HIV status, faced their diagnosis, and lives with HIV in order to take the pills. These adolescents had concentrated their lives on striving to live a normal life. The use of a variety of ways of dealing with HIV has helped them visualize themselves as a normal adolescent with a normal life. Because they see themselves having a normal life, taking or not taking their medications for HIV is also seen as a normal part of their lives.

The core category of *normal* appeared in almost all the interviews. Ten out of 13 adolescents referred to the word of normal in various part of the interview. This concept of normal was about trying to integrate their HIV status and treatment with their lives. Although HIV has changed the life of these adolescents, they intended or struggle to try to live a normal life as possible. This concept of normal was used by this population when referring to themselves or their own description, definition or desire to be normal. Some of the participants did not focus their lives in HIV, they do not think too much about having HIV. The concept of normal was used when referring to: their life, being with friends, doing the same activities that their friends
do, activities done to manage the HIV, activities done (routines) to take their medications, how they see their HIV, what does it meant to have HIV, and HIV as a disease as normal as others. It was also about how was the feeling when the HIV diagnosis was disclosed to some of the participants. These PRHPA refer to normal when talking about wanting to be normal and not taking pills every day without knowing why. Finally, taking the medications was seen as normal to some adolescents and part of life and having HIV.

Camila talked about normally when she referred to:

“Before knowing that I had HIV I was like a normal person it does not care about anything. Now I have to take the pills…” She also referred to the concept of normal when saying:” There are people that live normally and have it (HIV) and live normal and happy.” She also said: “You can be happy like a normal person and live with HIV.”

When David talked about his meaning of having HIV he said:

”To keep having a normal life. To keep doing normal activities, keep doing what you have always done, just like if you do not have anything. I keep playing normally. I keep doing things normally, I take the pills when I am doing something and remember. Having HIV does not make me feel different; I am still normal. I am calm and I do not think about that.” Finally he also referred to normal when he was asked about his disease: Now it is normal; the virus is low.”

At the end of this process of analysis, although the concept of normal was used to refer to different aspects, what these HIV-positive adolescents really want is to live their lives as normal as possible with HIV. To be able to do this they struggle every day to live a normal life.

Four major categories were identified that described how this process takes place. The four major categories were: Learning about their HIV Status, Facing the Diagnosis; Living with HIV; and Taking the pills. Each category had subcategories.

This process started when these adolescents were told their HIV status. Although is it a process, as it can be seen in the diagram, it is a dynamic one meaning that this adolescent moves
from one stage to another, after being told about their HIV status, but also returns to the beginning because he/she is always, day by day, *facing the diagnosis, living with HIV and takes or does not takes the pills*. *Learning about their HIV status* is when the process starts. It is the beginning of this process that starts at the age when the adolescents are told of their HIV diagnosis (disclosure). The moment of the process of disclosing the HIV status brought different kinds of emotional distress to these participants. The emotional distress experienced by this adolescent played an important role that will guide how he/she will live with HIV. This emotional distress continues every day as they are *facing their diagnosis*.

*Facing the Diagnosis* is followed by *Living with HIV*. *Living with HIV* is about a set of ways to deal that emerged to help this PRHPA live normally with their HIV. These ways of dealing, which are ways to strive for a normal life, help in the process of searching for a balance and strength that will at the end provide for a normal life.

The last part of this BSP, *Taking the pills* will be reached by means of the individual effectiveness of those ways of dealing. Through the process of data analysis some factors related to the process of *Striving to Live a Normal Life* were identified. These factors were: family, peers, healthcare providers, knowledge and fear of discovery.

The following is the diagram where this BSP can be seen. It can be seen in the diagram the four main categories identified after the process of constant comparison of the collected data from each interviews. The two ways arrows mean that the category has a dynamic relationship between them that goes both ways. For example, *facing the diagnosis* is related to *living with HIV* and vice versa. At the same time *living with HIV* is related to *taking the pills* and vice versa.
Taking the pills is related to *facing the diagnostic* and vice versa. Surrounding this whole BSP is the core concept of *normal* which it is in all the steps of the process.
FIGURE 2. Striving to Live a Normal Life
Learning About Their HIV Status

First of all, it should be understood that these particular participants were all perinatally infected with the virus. This means that they have lived all their lives with HIV and most of them have been on ARV medications since the time they were born. Another peculiarity is the fact that due to the nature of this disease, most of them do not live with their biological parents. They have lost one or both parents due to AIDS and have been raised by a legal guardian that most of the time is a blood related family member.

Disclosure

Learning about their HIV status starts when the person was told that s/he had HIV. After that, facing the diagnosis is a daily experience; it never ends. When the youth first learned that s/he had HIV, there was almost always emotional distress. For some participants this process started between the ages of 6 to 12 years old. For some, this process started between the ages of 14 to 16 years old. In some of the participants, HIV status was told by a legal guardian first.

Disclosure was a different and unique process for each adolescent. As described by Estefany, her legal guardian waited until she thought that she was mature enough for disclosure.

“Well because they did not know how I was going to react, how I was going to be, and they decided to tell me at the age (15) that I will understand and had the capacity to understand.”

Disclosing the diagnosis has brought to the HIV positive adolescents responsibility concerning their treatment. They know they have to take their medications in order to keep CD4 high, viral load low and avoid complications that will take them to the hospital. Disclosure has provided the opportunity for the HIV-positive adolescent to participate in their treatment with the HCP. Disclosing the diagnosis has given more knowledge of HIV to the HIV-positive
adolescents. Disclosing the diagnosis had answered some questions that these HIV-positive adolescents have had about why the pills every day, and why the appointments. After learning that s/he was HIV-positive, by the age of 14, most of the HIV-positive adolescents interviewed had more responsibility of their treatment. Some of these participants were begun managing their disease by themselves as soon as they were told that they were HIV-positive. It is the beginning of facing the decisions to take or not their medications. Because of this, disclosing the HIV status is related to adhering or nonadhering to medications.

This process, in most of the cases, was done in the presence of the legal guardian, and a healthcare provider that most of the time was the pediatrician, social worker and/or psychologist. HIV status was disclosed first by the legal guardian in 4 out of 13 adolescents and 7 out of 13 were told by a HCP with family members present. Only one discovered their diagnosis by means of reading some papers about it. One expressed knowing the diagnosis and staying quiet until months after it was disclosed in the clinic. Those disclosed by family members only, when attending to the clinic, and then HCP follow through the process. After disclosure it took time for the participants to understand. Different approaches were used for disclosure. Some HCP used drawing and colored pencils, a cartoon storybook, and other used talking. The approach for disclosure depended on the child’s age and individual situation. Alejandro’s disclosure experience happened in the following way:

“There were all the doctors and the people that I know from this program. Also it was my mother, and brothers. They were in a circle with me. I was 4 or 5 years old. At the moment I didn’t understand but as time passed I understood. Then when I was 7 they told me in another way so that I can understand my health situation. I had a lot of questions about what do I have that were answered as time passed. When I was 8 or 9 then it was hard because in school they gave you project to do about HIV.”

Camila’s experience was different but it still was a process:
“My dad told me. I think it was in the car or at my home. He told me because I asked him why I have so many appointments. He told me that I have a condition that wasn’t easy. He told me that I have small animals in my blood and so forth. Then he took me to the clinic and there they continued to explain to me what I have until I understood. I understood when I was 10 years old the meaning of this disease and what I was against.”

After disclosure for the first time, for some adolescents the process was followed during the next few appointments. As can be seen, each adolescent experiences the disclosure differently. Age and maturity was considered by some family member or the legal guardian. Also disclosure came for some adolescents because of treatment related questions, anticipation of events, and curiosity.

*Emotional Distress*

Learning about their HIV status had bought to this population a variety of emotional distress as they responded after disclosure. This emotional distress included feelings of anger, sadness, loneliness, depression, calm, confusion, and ambivalence. Some experienced the “there is no choice,” “why me,” “God has a purpose,” and “it is normal like having diabetes or high blood pressure.”

Benicio said:

“I felt regular. I felt sad. I do not know, afterwards I kept going I did not put my mind on it. I live my life normally.”

Ninoshka felt normal and expressed that her grandmother's reaction was pretty bad because she cried and Ninoshka had to comfort her.

“I think that my grandmother kept the secret for so many years that when I was told she felt relief and maybe scare that I would judge her or fight with her because she did not tell me before. But I felt normal.”

When being disclosed, nine adolescents had negative feelings: three felt between confused and ambivalent; two felt surprised; two felt sad; one felt deceived; and one felt bad.
The other four had feelings not expected by this researcher. These feelings were: calm and normalcy.

**Facing the Diagnosis**

Facing the diagnosis describes how PRHPA’s face the everyday experience of having HIV. It was about what was difficult or easy about having HIV. When it was asked to these adolescents the question: What has been the easiest or the most difficult part for you in having HIV?, most of them came with their meaning of having HIV.

**Meaning of Having HIV**

Among the acknowledged meanings of having HIV, these adolescents expressed positive meanings. Some expressed the meaning of having HIV in a philosophic or abstract way. For example, most expressed hope. Others said: “Life is the same with or without it; HIV is a challenge that you can face; nothing changes; life is normal; it is not the end of the world; life goes on as a normal process; you are a normal person; keep doing normal things like if you don’t have it.”

Others expressed it in a way of referring directly to HIV. For example, some comments were: “It is a responsibility; nothing is easy with HIV; you can live with HIV; support is important; search for support; you can be a normal person when having HIV; take the pills and you can live; going to the appointments is important; it is a disease that needs to be accepted so that you can improve; it is a virus that does not go away with any medications; difficulties problems with boy/girlfriend; and it changes the sexual relationships.” Other meanings of having HIV were: that is it like having a cold or pneumonia because if you don’t take care you can go to a hospital; not taking the medications will kill you, but you can live with HIV by taking the
medications. As noted previously, these messages are all positive, full of hope and ways to cope with this disease.

Alejandro expressed it like this:

“It is difficult in the loving matter. It is difficult in the society because not everybody understands what HIV is because I have had the experience of friends who think that HIV is the same as AIDS and that tomorrow you will be dead or you are a drug addict or an alcoholic or an aberration of the society.”

“It is not death, it is not the end; having HIV in these days is like having a cold or pneumonia, if you do not take care you go to the hospital. If you keep your treatment you are good, if not you die. You have to keep going in life. Life continues, there are beautiful things in life to live for; lots of experiences good and not so good…”

Benicio said:

“It is not the end of the world, life keeps going. Life keeps going; for me it is a responsibility to myself. The world does not end because you have a disease…”

Living with HIV

Ways of dealing emerged as a way or necessity to live, and manage HIV, limiting the impact of having an incurable disease while striving to live as normal a life as possible.

Ways of Dealing

The ways of dealing were described as the different behaviors that help these PRHPA avoided, diminished, prevent, eliminated and/or control the stress of daily life events. It is about how they face the daily demands of living with HIV, what they did in order to co-exist with HIV. Each PRHPA develops their own personal ways of dealing, depending on the existential environment that surrounds them: their gender, age, and support system, among other factors.

When analyzing the data collected from the interviews, the researcher noticed the variety of ways of dealing used by these adolescents. Some of these ways were common to various participants, but most of them used their own personal, unique and different ways. Some of the
daily life situations and reasons why these ways of dealing are developed and used by these PRHPA were: fear of rejection, fear of being stigmatized, taking medications daily, fear of disclosing HIV status, and wanted to be accepted by peers and others, who frequently had poor knowledge of HIV/AIDS.

Some of the ways of dealing used to face the daily demands of living with HIV by these adolescents, and that emerged from the data analysis, were: optimism, viewing themselves as a normal adolescent, viewing themselves as being the same as their peers, having future plans, belief in God, their family viewing them as not being different, questioning “Why me?”, going to church, developing a spiritual support system, having best friends, resignation and acceptance, establishing routines, seeking having fun, secrecy, telling lies, not taking their medications, being active in social activities, solving others’ personal problems, and becoming dependable to others. The use of such widely different and contradictory coping strategies demonstrated the complexity of this behavior.

Estefany uses secrecy, denial, viewing herself as being the same as anybody, optimism, nonadherence to her treatment, telling lies, God, and having future plans.

“Only my mother and grandmother know about my HIV. My brother lives with me but he does not know. My friends do not know either. You cannot say what you do not have. HIV has a cure and a remedy. You cannot go back; you have to keep going because life continues. The truth is that it is not something out of this world. God is the doctor by excellence. He can cure and he can free us.”

Hilda uses optimism, calming self-statements possibly for denial, secrecy, and forgetting as her ways of dealing.

“No, I don’t put my mind in my problems. I live my life like that, normal. I try to overcome it and be positive. It won’t bother me. My life hasn’t changed because I have HIV. After I knew my diagnosis, I have not told anyone. I have kept it secret and it will
be a secret so that I do not get rejected. My brother and grandmother live in my house and they do not know it. Not even in school do the teachers know.”

As can be seen, there were a variety of ways of dealing used by these PRHPA. Table 1 is a summary of the most common ways of dealing used by these adolescents, and their meanings.

**TABLE 1: Summary of the Most Common Ways of Dealing Used and Their Meanings**

<table>
<thead>
<tr>
<th>Ways of Dealing</th>
<th>Description</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism/Hope</td>
<td>Having confidence, looking forward with confidence. Not giving up. Keep going, stand up, and keep trying, expecting things will get better if you keep going. Believing that you can do it. Having HIV is not the end of the world. Life continues. It is not easy but you can live with it.</td>
<td>12 (92%)</td>
</tr>
<tr>
<td>Being with friends/Support</td>
<td>Is important. Having close or best friends to talk about when depressed. Is about hanging out and feeling the same as they do. Sharing about your feelings, and everything about HIV. Finding other friends if they leave. Treating you like any normal friend.</td>
<td>11 (85%)</td>
</tr>
<tr>
<td>Secrecy</td>
<td>Choosing who to disclose to. Was about not trusting friends, people at school and not even family members. Not telling people about the HIV status to avoid rejection and being stigmatized. Not disclosing because people are not well educated about HIV. Not wanting their friends to know because it was what made them different. Sometimes a family member wanted to keep disease a secret.</td>
<td>9 (69%)</td>
</tr>
<tr>
<td>Having future plans</td>
<td>Was about viewing themselves in the future. Having a plan that will guide them to the future. Most future plans were about engaging in studies. Others were about getting a job, getting married and having children.</td>
<td>7 (54%)</td>
</tr>
<tr>
<td>Telling lies</td>
<td>Was about lying regarding why and what were the medications for, to people who had not been disclosed to. It helps this adolescent avoid and prevent being rejected or stigmatized. It also prevents them from disclosing. Telling lies was about the medications were seen normal by these adolescents.</td>
<td>5 (38%)</td>
</tr>
<tr>
<td>God, spiritual support</td>
<td>The adolescent’s religious beliefs and faith about God. Having faith that God will cure them from HIV. It was about believing that their HIV was all a part of God’s plan, even if they did not understand why.</td>
<td>5 (38%)</td>
</tr>
</tbody>
</table>
Taking the Pills

All the while an HIV-positive adolescent is facing his/her diagnosis on a daily basis and living with HIV through the use of different, individual, and very personal ways of dealing. Simultaneously there is also a moment, or perhaps two, everyday where he/she has to take their HIV medications. These PRHPA who were all perinatally infected by the virus have been on ARV medications almost since they were born.

Ninoshka described it almost the same way as Alejandro:

“I think I have been in my treatment since the day I was born because I was born with the virus that I had from my mother.”

As the interviews progressed, in time it became clear that most of the participants were not taking their medications all the time. Being responsible for taking their medications, the participants said, allowed them to make the decision to take the medications or not. Most of them, 11 out of 13, admitted to not taking the medications sometimes. For some the fear of rejection and stigma made them take the medications at home most of the time or do not take them if they are out of home. They expressed and know the consequences of not taking them as prescribed, they want to live, but they still do not take them properly.

The following is a discussion of the routines that these HIV-positive adolescents have established to take their medications and the barriers that prevent them from taking their medications.
**Routines**

Routines that were established by the participants’ legal guardian were adopted by these HIV-positive adolescents. These routines were seen as part of and normal as life itself. They were standard and regular activities done every day to remind them to take their medications. Routines were about always having a pattern at home, of taking their medications every day. It facilitates the possibility of taking their medications because it was established to be done at home where it was secure to take them. These routines were done according to the adolescent lifestyle. The participants referred to this routine as the same as having breakfast or going to school because when and where the routine is given is essential. Because of this, these routines are seen as part of a normal life. Lya (age 15) described it in detail, as follows:

“A normal day, well, I wake up I have to eat breakfast because if not I cannot take the medications because they will make me feel bad. Then I go to school, after school I do my homework, I get a shower, eat and at night I take the medications. It is already like a routine, a normal life because the most important thing is to take the medications because without the medications I can get sick.”

Zaida described it also as a detailed or standard procedure:

“The first thing that I do is pick out the clothes that I will put on in the morning; then I shower, then after I shower I go to my room and take my medications, I show them to my father, and take my medications. I stay a while in my room until I am not sleepy, then I get dress, take care of my 2 dogs… After coming from school I eat dinner, I rest, do my homework, do things my dad tells me to do, take my medications and go to bed.”

**Barriers**

Barriers were about what interferes in the life of these HIV-positive adolescents that keeps them from taking their ARV medications. These barriers interfered with them taking their medications at the correct time on a certain day or for several days and even months. So they have some knowledge but it seems they haven’t internalized the information, so these patterns of
medication taking, medication beliefs, move to see this as part of the basic social process of striving to live a normal life. Not taking their medications is seen as normal as taking them. The barriers they identified were: forgetfulness, bad taste, changes in daily routines, do not want to take them in front of their friends, got tired of taking them, got bored with taking them, being out in the streets with peers, staying out of their house for the night or weekend, doing something else, and being out of medications.

Benicio’s barriers were forgetfulness and hanging out with friends:

“I can see my bottle of pills and forget to take them. It is just like that, normal. I also forget them because I say I will take them later and later is that I forget. I have to be aware and see the time to take the pills. I say to myself: do not leave it for later because you will forget.”

“I get invited to hang out. I live in this barrio and I have a cousin that lives side by side to my house. He has a PlayStation 3 and because I am intent on playing the game, then I forget the pills.”

Camila’s barriers were, forgetting, change in daily routine, and getting tired of taking them:

“Sometimes I forget and sometimes I fell asleep and forgot. Sometimes I wake up in a hurry and I have to get to my job so I cannot take them. There was a time that I did not take them because I just got tired of taking them. It might pass 1 or 2 weeks and I do not take them. Then I start again as always.”

Factors Related to the Process of Striving to Live a Normal Life

During the analysis process of the data collected from the interviews, data emerged that were identified as the factors related to the process of striving to live a normal life. These factors were: family, peers, health care providers, knowledge and fear of discovery. The following is a description of each factor as described by the participants.
Family

Family is important in the life of most of these HIV-positive adolescent. Because of the nature of HIV, the traditional family system has been disrupted. One reason for that disruption is, as described previously in this chapter, that most of these adolescents do not live with their biological parents. But their families are composed of mostly blood relative family members. Other family members have taken on the responsibility of raising this adolescent. Most of the time, it is the grandmother or grandfather. In this study, 6 out of 13 are being raised by one or both grandparents. Another reason for that disruption is that this population has to travel to regular medical appointments. This means that the family needs to spend extra money for at least transportation and food. Evidence of this was that, on at least 4 occasions, the researcher went to the clinic and the potential participants had not come to the clinic because of they lived far away and did not have enough money for gas and food.

Support

Support provided by family is very important, positive and significant for most of the participants. Most of the participants (12 out of 13) agreed that support is important and needed to deal with HIV and live a normal life with HIV. Support from family takes place in a different way than from friends and health care providers. For example, some ways family give support is: by telling the HIV-positive adolescent to take the medications; taking them to the appointments; telling them how much they care and are loved; telling them that they are not special, they are the same as others; treating them as any other person; encouraging them to keep studying for the future; buying the medications; taking them to church; providing other group support, like in church; and providing money to buy things. Before disclosure some family members’ way of
supporting the treatments was to give the medications. Now, after [disclosure, although most other things are the same, their strength is to be a reminder to the HIV-positive adolescent to take the medications and watch them take them.

Having a family provided to these HIV-positive adolescents the environment that supported their struggle to live a normal life with HIV. Support plays an important role in this matter. Support can be positive or negative. When support is about being told many times everyday to take the medications it is considered by these adolescents like a negative support; it is family overinvolvement and the HIV-positive adolescent feels angry and annoyed about it. That kind of support, to the adolescent, does not provide for independence and autonomy; and it reminds them about the disease.

Ninushka talked about her support saying:

“Of course my family has been of great support. I think that it is one of my biggest motives why I am still being able to keep going forward with HIV. My family accepts me as I am and with what I have so I do not care if others reject me because others do not give me anything. My family gives me everything I need to live with HIV and that is what matters.”

Disclosure

Two types of disclosure were observed concerning the family: family participation in the process of disclosure of HIV status to the adolescent, and disclosing to other family members. As discussed previously, 12 out of 13 HIV-positive adolescents’ family members were present in the process of disclosing the HIV status to the adolescent. Their participation was active in the sense of being the first to disclose the diagnosis to the adolescent; or being in the clinic room at the time the health care provider disclosed to. As discussed also previously, family support after disclosure and throughout the adolescence of these participants has been important.
Disclosure to family members has to do with trust. Diagnosis kept as a secret to some family members was found in some interviews. It was found that some HIV-positive adolescents lived in a house with some family members who do not know the diagnosis. Disclosure to family members brought to the HIV-positive adolescents the fear of being rejected. Some felt that not disclosing prevented or avoided stigmatization and being rejected.

Estefany said:

“Of course my mother and grandmother know about my HIV, but not my brother and he lives with us. Maybe he will feel bad or embarrassed.”

Gladys said:

“Not all my close family knows because my grandmother and grandfather do not want them to know because they do not know how they will react. They say that maybe they will reject all of us or start talking nonsense about it. So we prefer to keep the secret.”

Loss

Loss was about losing a family member due to AIDS. All the participants have experienced the loss of one or both parents due to AIDS. Most of them, 10 out of 13 have lost one or both parents by the age of 8 or younger. Most of them, 7 out of that 10 have memories of the parent lost. Most of them expressed feeling sad because of the loss of one or both parents. These bereavement issues may be related to other emotional or psychological issues and depression in this population.

Maria described it when she said:

“Yes I have lost both of my parents because of AIDS. My mother died] when I was young and my dad too. Sometimes it makes you feel lonely and sad. Sometimes I just do not think about it. It is not easy and it is not normal but you make it normal. At the end I am not the only one that has lost the parents because of AIDS or any other thing and I am not going to be the last one.”
Ninushka said:

“Well yes it is hard not having your whole family with you. It is difficult to live normally but I have my grandmother. My mother died when I was one year old so I never met her. She had AIDS but died of an asthma attack. My father, I never met him or his family.”

Friends

Having friends was very important to some of these adolescents. It was about having their acceptance and feeling part of the group. It was about not being alone, and knowing that they have their support. When doing the analysis of the interviews it was observed that out of 13 participants, only five have disclosed the diagnosis to at least one friend. Those who disclosed to one or more friends considered it very important to have a friend that knows about the disease and supports you.

Benicio described this when he said:

“I met my friend in high school and since the day we met he told me that we were like street brothers. We were always together in school for good and for bad. We did things together in school. Then one as time passed I thought about telling him and so I told him and he told me that it does not matter. He accepted me as I am. It was important to me.”

Camila said:

“Not that many friends know about my HIV, but those who know have accepted me like that. I feel relieved that I have them.”

Disclosure

Disclosure to friends, as to some family members, has to do with trust. Disclosure to friends, like to family members, brought to the HIV-positive adolescents the fear of being rejected or that others would start talking about them. Being with friends was a source of stress and worry, influencing not taking their medications. Some of these adolescents felt fear that
friends would question them about why they take medications and being then obligated or pressured to disclose to them.

Although they expressed the importance of friends’ support, they also expressed being cautious when disclosing to one. Trust had a very important place when disclosing to a friend. Also, besides trust, the friend’s knowledge/opinion about HIV was important. Not all friends knew the diagnosis because of the wrong misconceptions they had about HIV and the fear that after disclosure they will leave, as it has been previously experienced by some of these HIV-positive adolescents.

Alejandro said:

“I consider my close friends like brothers. But they do not know that I have HIV because they are not well educated in HIV. They have liked a stereotype of that (HIV) and maybe they can reject me. They are not clear about it.”

Maria picks whom to disclose to.

“I pick to whom I should tell about my HIV. I have told some of my friends. In the beginning they felt sad about it. But they took it well, because I picked very well who to tell. If I tell someone it is because it is very important to me or to somebody that I know. I pick because society is very ignorant and when some people know they will not talk to you or touch you.”

Support

Support given by friends was about; feeling proud, keep going, it is not the end of the world, saying it does not matter, don’t worry, I care, I am with you, we can make things together, we can hang out together, treating you the same as others, among other things. Support given by friends is very important to this population. Most expressed that it was very important to at least have a friend that can give you support.
Zaida has a confidant best friend that supports her.

“I have a friend who knows. It is a confidant friend. We are best friends. We are super friends, we talk always on the phone and always he is worried about me and me about him. I also have 2 best friends that know and we are strong friends. They told me that they are there to support me and that anything that I have to tell them that they are there for me.”

Lya has church friends and they are supportive with her.

“My friends from church are very important. I have 2 best friends in church and every time I stayed in their house they reminded me to take the medications. They always are worried for me and it is good to know that you have friends that care. Knowing that although you have HIV, I have friends that are worried about me. This is important to me.”

**Health Care Providers**

Health care providers (HCP) were the ones that most of the time had disclosed to the HIV-positive adolescent. Of the 13, 8 had their disclosure from a health care provider. This was the pediatrician, the social worker and/or the psychologist and once the nurses were included. For some of the participants, the HCP have been very important because they had answered questions from this population while treating them and they have provided in different ways support to these adolescents.

The following is a description of what the researcher observed at the GAMMA Clinic concerning the HCP and others workers. This is described in this section because it has to do with the health care services provided to the participants and in some ways it has to do with how this population views the HCP and their professional competence. These observations were done while waiting for potential participants to arrive at the clinic.

When the patients arrive at the clinic, the first person they see is the receptionist. Most of the time, she receives the patient with a hug and a kiss because she knows all the patients of the
clinic. She always asks about some of the family members of the patient, about how are they doing and what is going on and what is new. After that conversation she calls the pediatrician or the social worker or the nurse that takes the blood samples or the psychologist to see who is available to see the patient the moment he/she arrives. This means that the patient does not have to wait so long for being taken care of.

The patients and their family member seem comfortable when arriving at the clinic. Some, if they have had a party, will bring the pictures of it. Others bring some food to the people that work at the clinic. The HCP that will attend the patient will first walk from her office to the counter and receive the patient. Her way of receiving the patient and the family is the same as the receptionist does. A family environment was observed at the clinic. Of course most of these patients have been attending the same clinic since they were born. This environment helps provide health care to this adolescent, in terms of trust, confidence and a feeling of comfort.

Support

Health care providers’ support was about being there for these adolescents, answering their questions, and helping in the adolescents’ care.

Gladys said that her support from the HCP is enough:

“They support me enough. I have a card that they gave me here where they put the names and quantities of the medications just in case I forget…”

Camila said about the support that she receives:

“Here in the clinic I receive a lot of support and they oriented me. They have support group but I do not go because I live far.”
Knowledge

This category has as sub-categories medication knowledge, and HIV knowledge. For these adolescents, at least knowing the name of their medications, when to take them, and having some basic knowledge of HIV was part of the BSP of striving to live a normal life.

Medication Knowledge

Most (10 out of 13) HIV-positive adolescents knew the name of the different medications they were using, and when to take them. Only three (3) knew the medications by color and shape, which was included as knowing them. They knew them by color and shape and they knew when to take them. When to take them meant: when they woke up in the morning, and before going to bed; or, before or after breakfast and before or after dinner. All the participants have made this part of their life routine. They know that their medications help control the disease by keeping the CD4 high and the viral load low or almost undetectable.

So they have some knowledge; but it seems they haven’t internalized the information, so these patterns of medication taking, medication beliefs, have not motivated or convinced them to see this as part of the basic social process of striving to live a normal life. They know the risks of not adhering and the benefits of adhering but the risks weights more than the benefits.

Camila also knows her treatment by name:

“Well I take Norvir, Invirase, Epivir, Zerit and Protonix that is for the pain. I take it before, 5 minutes before then I take a shower and after I take acid folic. I take them all in the morning, except the Epivir that it is at night and I take 2. The rest are twice a day and Protonix is once a day.”

Jose knows his treatment by color:

“One is brown, one is white and blue, and one is like yellow and white. Four in the morning and 3 in the afternoon. I take 2 brown in the morning, one white and
blue and one like yellow with white. In the afternoon I take 2 brown and one white and yellow.

_HIV Knowledge_

Most of them know the basics of HIV such as, the need to practice safe sex; how it is transmitted, what is needed to take care, why it is necessary to take the medications in order to live, and what are CD4 and viral load. All this knowledge they have from their HCP, their legal guardian and the Internet. They said that when they had a question they trusted asking the people who work at GAMMA Clinic where they attend for their healthcare. They feel comfortable asking questions in the clinic.

Some (4) of the HIV-positive adolescents believed that HIV can be cured. It is more likely that these adolescents are in denial of their disease. Most of them consider cancer to be a worse disease than HIV because people can die from cancer, their hair falls out and treatment makes people feel worse. This attitude or meaning can be considered as: having the knowledge and believing in it, but not understanding it. This can be understood as part of the BSP of striving to live a normal life; where they compared their disease with another, perhaps, to decrease stress or anxiety.

Alejandro talked about having sex with protection:

“We had sex and everything was as it should be with respect to protection and preventive measures so that I will not be contagious to her and now she does not have nothing; she does not have HIV nor nothing.”

Maria said:

“This is what keeps me from getting sick and I know that until now it is what I need so that the condition will not attack my body. My CD4 that are my defense against this virus are high and the virus that we call viral load is undetectable.”
Fear of Discovery

The category of fear of discovery, identified and related to the BSP of striving to live a normal life, had as sub-categories: the fear of rejection, and the fear of being stigmatized. Each will be discussed below:

Fear of Rejection

It was experienced and discussed by all the participants. Not only the fear of being rejected; but of actually being rejected by their family members and/or friends. For most of the HIV-positive adolescents, fear of being rejected by family members and friends happened because of the fear people have of the disease, and the poor understanding the general public has of it. There is confusion about the difference between having HIV and having AIDS.

The meaning of rejection is experienced in different ways. Boy/girlfriends have left; and some family members ignore or do not talk or talking is limited to the HIV positive adolescent. Other evidences of actions done in order to avoid or prevent being rejected are: hiding the medications in the home, and hiding in order to take the medications (bathroom or room). Taking the medications only at home, as all the HIV-positive adolescents in this research did, is evidence of the fear of rejection and the secrecy.

Fear of rejection is one of the main reasons for not disclosing to family members and/or friends. Having HIV is a secret; and though that is mostly unspoken, to them it is a shameful secret. These children were cursed from birth by a condition not of their making or choice; yet they will spend their whole lives in its shadow. This rejection, or a feeling of the fear of rejection, might be present at home, church, school or outside in the streets. It was always present in the mind of these HIV-positive adolescents. Besides an unwillingness to trust others,
the poor knowledge of the general public about HIV is another reason for the fear of rejection that these HIV-positive adolescents have and why disclosing is not possible for some. Because of this, fear of rejection or of being rejected this can be a factor contributing to the decision to take the medications or not.

*Stigma*

This concept of stigma, although it was not mentioned as such by any of the participants, was nevertheless identified as the interviews were analyzed. It came from talking to these adolescents about their disease; it was also about avoiding being kissed or touched. Taking your medications at home is only one way of avoiding being stigmatized. Hiding medications where no one can see them is another way; and another reason for not disclosing to family members and friends. Lying to friends about medications is done to avoid stigmatization and rejection.

Poor general knowledge about HIV is also a reason for stigma. Wrong misconceptions about how HIV is transmitted, by kissing or touching, is another experience this population has had and a reason they gave for feeling stigmatized. Some of the participants said that some people felt sorry when they found out that the adolescent was HIV positive because it is a cruel and horrible disease. People have labeled them.

Some HIV-positive adolescents in this study admitted feeling guilty and/or ashamed of having HIV. This was a way of feeling stigmatized. Stigmatization can interfere with the decision to take the medications or not, as it also is a part of the process of striving to live a normal life. Stigma is the result of poor knowledge of HIV from people with ignorance and fear of HIV. Unfortunately, it correlates with the decision among the HIV-positive adolescents to adhere or not to adhere, in order to not take the medications in front of others, to avoid being
asked embarrassing questions. They do not take their medications, and decide to not take them deliberately, when they are afraid that friends or family might discover their disease. This is evidence of their struggle to live a normal life.

Summary

Chapter four presented the results of this study. It started with the identification of the sample and the characteristics of the participants presented in various tables. It also discussed the process of how the data was collected and analyzed with the identification of codes, sub-categories, categories, major themes and the core concept. This discussion was followed by the presentation of the substantive grounded theory emerged from the data analysis; with the basic social process of Striving to Live a Normal Life. This emerged substantive grounded theory was presented as sub-categories, categories; major themes and core concept were identified and evidenced. Finally, the chapter discussed how trustworthiness for the results was met through the use of different strategies.
CHAPTER FIVE: DISCUSSION AND RECOMMENDATIONS

In this chapter the research questions will be answered, discussed and related to the literature. Implications of the study findings and concerning with other nursing research, theory and practice will be established. The chapter concludes with a discussion of the strengths, and limitations of this study, recommendations for future research and a summary of the chapter.

Answer and Discussion of Research Questions with the Literature

Research Question #1: What are the basic social processes of medication adherence in Puerto Rican youth who are HIV positive?

The basic social process (BSP) of medication adherence in Puerto Rican youth who are HIV-positive was, \textit{Striving to live a normal life}, with the core category of normal. This process of \textit{Striving to live a normal life} with the core category of normal, defines and describes how these Puerto Rican HIV-positive adolescents (PRHPA) \textit{learned about their HIV status, faced their diagnosis, and lives as HIV-positive adolescents}, in order to \textit{take the pills}. These adolescents have focused their lives on striving to live a normal life. The use of a variety of ways of dealing with HIV has helped each of them visualize themselves as a normal adolescent with a normal life. Some of these ways of dealing can be considered as behavioral strategies (Rehm, & Franck, 2000). Factors classified as family, friends, health care providers, knowledge and fear of discovery were related to this BSP.

\textit{Striving to live a normal life} was about trying to integrate their HIV status and treatment with their lives. Although HIV has changed the lives of these adolescents, they intended to or struggle to try to live a normal life as possible. This concept of normal was used by this population when referring to themselves or their own description, definition or desire to be
normal. Some of the participants do not focus their lives on having HIV; they do not think too much about having HIV. The concept of normal was used when referring to: life in general, being with friends, doing the same activities that their friends do, activities done to manage the HIV, activities done (routines) to take their medications.

Normal was also how they wanted to feel when the HIV diagnosis was disclosed to some of the participants; it was about wanting to be normal and not having to take pills every day without knowing why, and why taking the medications was seen as normal by some adolescents and a part of life and of having HIV. The performance of daily activities, having future plans, going to school, having a job, being a future father were among the normal patterns that these PRHPA follow that made them try to see themselves as normal like any other adolescent. This helped them to manage and live with their HIV. How they perceived their HIV, as well as asking themselves the question, “What does it mean to have HIV?” or “Why do I have HIV?” were also part of what they considered as normal. Each PRHPA in this study had their own view of what they considered normal; but in general, there were also similarities. Taking their medications was seen as a normal activity because it had been established as a routine: every morning and evening, or before going to bed. There were times that those routines were changed, and taking their medications was not possible, but this was also considered normal.

The concept of normalization in the context of chronic diseases has been in the literature since the 1950s (Davis, 1961; Schwartz, 1957). Both authors, Davis and Schwartz, gave the concept a cognitive perspective as a process underlying the person’s view of the situation (Knafl & Deatrick, 1986). The concept was used in studies about how families manage or cope when they have a member with a chronic disease (Knafl & Deatrick, 1986). Studies in the 1970’s,
based on a cognitive perspective, helped to establish its theoretical underpinnings. The concept was used in studies related to families with disabled, retarded, and thalidomide children (Birenbaum, 1970, 1971; Voysey, 1972). By 1986 a concept analysis of normalization had been done with families managing a member with chronic conditions (Knafl & Deatrick, 1986). Since 1986 the concept of normalization has mostly been used by, and identified with, parents or family members taking care of a child with a chronic disease or disease.

By 1999 another concept analysis was done in order to refine the previous one (Deatrick, Knafl, & Murphy-Moore, 1999). Here the components, attributes and definition of normalization included an acknowledgement of the disease and its potential to threaten: the lifestyle of the child’s and family’s definition of normalcy; performing parenting behaviors and routines, considering them normal; the development of treatment routines that felt normal; and the interactions with others based on the perspective that the child and family were normal (Deatrick, Knafl & Murphy-Moore, 1999). However, these attributes of normalization were identified within chronic diseases and family contexts.

The concept of normalization describes a process by which an individual with a disability can and should have access comparable to the social involvement of an individual without that disability (Wolfensberger, 1972). Others have defined it as a socially constructed process in which each social group defines reality (Seligman & Darling, 2007). In this study, PRHPA as a social group described their reality of living with HIV as being normal. They considered normal activities to be those that any adolescent of their age would do. This description is related with the previous definition given by Seligman & Darling (2007) because it is how this social group has described the concept of being normal.
The findings of this study suggest that the PRHPA each have a different personal meaning or understanding of what is normal. They modify their definition daily in accordance with the activities done that day. Several studies have found that in families with children or adolescents with a chronic disease, that the concept of normal has no standard meaning and that when living with a family member with a chronic disease, they have to modify the meaning of normal activities and behaviors to fit into their actual lives (Clarke-Steffen, 1997; Deatrick, Knafl, & Walsh, 1988; Robinson, 1993).

To feel normal is about the identification of a pattern that is seen as standard, usual and typical (Wise, 2002). When adolescents concentrated their lives on being as normal as possible, this allowed them to decrease their perception and experience of their problems and to live their lives as normally as they could (Wise, 2002). The PRHPA have concentrated their lives on activities, routines and a variety of coping strategies that have helped them live their lives as normally as they could be. Having and living with HIV has taught these adolescents to give their daily activities a routine in order to keep doing things normally. Keeping the secret of their diagnosis and not talking to others about having HIV, because of the fear of being rejected and stigmatized, were examples of how they have had to integrate their lives with having HIV. In the only study found, where the concept of normality was identified, with HIV-positive adolescents from France, 75% considered themselves as having a pleasant life because they had a normal life where the secrecy and silence about HIV were the price for their normality (Trocmé, Vaudre, Dollfus, & Leverger, 2002).

For PRHPA, not taking their medications because of, among other reasons: a change of routine, being late for job or school, being bored or tired of taking them, was also seen as normal.
Activities not normal for a healthy adolescent, such as taking pills every day, have made these PRHPA establish a routine or adopt it from their legal guardians, that is seen as being as normal as going to school, hanging out with friends, and going to work, among other daily normal activities. Among liver transplant adolescents, these abnormal activities of taking pills every day had also caused taking their medications to be integrated into their daily routine; and they compared them to having breakfast, going to school, among other daily routines (Wise, 2002).

Because most of the past studies using or identifying the concept of normalization have been with families, the experience of adolescents with chronic diseases to normalize their life and disease has not been well studied (Malbasa, Kodish, & Santacroce, 2007). When searching the Internet, 17 studies, using adolescents with chronic diseases, were found in which the concept of normal or the process of normalization was identified (Admi, 1996; Atkin, & Ahmad, 2001; Christian, & D’Auria, 1997; Earle, Rennick, Carnevale, & Davis, 2006; Elliot, Lach, & Smith, 2005; Gallo, Schultz, & Breitmayer,, 1992; Hokkanen, Eriksson, Ahonen, & Salantera, 2004; Horne, 1999; Huus, & Enskar, 2007; Kim, & Kang, 2003; Malbesa, Kodish, & Santacroce, 2007; McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004; Rechner, 1990; Roux, Sawin, Bellin, Buran, & Brei, 2007; Snethen, Broome, Bartels, & Warady, 2001; Trocmé, Vaudre, Dollfus, & Leverger, 2002; Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). None of these studies used a quantitative methodology, which it came because of the complexity of the concept. All these studies used different qualitative methodologies and identified that being normal, living a normal life, living a regular life or getting on with life, was what these adolescents experience. In this study, striving to live a normal life was found as the BSP in HIV-positive adolescents. PRHPA want to live a normal life although they have HIV.
In some of these studies living a regular life, living their lives as normally as possible and keeping a normal life was about doing the same things their friends do and not having to live with routines. They want to be spontaneous and have overnight visits like their friends but without having to think and plan in advance. It was about being independent and using coping strategies that will balance their concerns about their disease with the desire to live as normally as possible (Atkin, & Ahmad, 2001; Huus, & Enskar, 2007; Snethen, Broome, Bartels, & Warady, 2001). Some of the PRHPA also like to stay overnight but some hide when they take their medications. Hiding was a strategy they use to cope with the chronic disease and not having to disclose it.

In other studies, decreasing the sense of being different from their friends, the phrase life around, a desire for normalcy and feeling normal were really about being different, feeling not normal, pursuing normalcy but not reaching it and getting on with life. It was about being identified as a patient only in a health care setting and that the chronic disease was not the central identity in their lives. Therefore, they prevent their chronic disease from interfering with their daily activities. Adolescents with chronic diseases who participated in these studies used different strategies to try to be normal (Admi, 1996; Christian, & D’Auria, 1997; Elliot, Lach, & Smith, 2005; Hokkanen, Eriksson, Ahonen, & Salantera, 2004; Rechner, 1990). PRHPA also deal with their HIV every day in order not to miss any normal activity such as hanging out with friends. HIV also was not the central role of their life. Some even forget they have HIV or do not think about it in order to deal with it.

Also, in another study, treatment adherence was an obstacle to normalcy or “being like everyone else.” Their treatment was a barrier to participating in “normal” activities (Malbasa,
Kodish, & Santacroce, 2007). For PRHPA, taking their medications was also sometimes a problem, especially if they were staying at a friend’s house; or if they were outside with friends and it was time to take their medications. If they were late leaving for work, doing daily activities such as adhering to their medication regimen could be neglected.

Striving to live a normal life was found to be a goal in this study with adolescents with HIV, as it was found in other studies with adolescents with thalassaemia major or sickle cell disorder, cancer, liver transplant and epilepsy (Atkin, & Ahmad, 2001; Elliot, Lach, & Smith, 2005; Hokkanen, Eriksson, Ahonen, & Salantera, 2004; Wise, 2002). Adolescents with liver transplants saw themselves as healthy and as normal as other adolescents without a chronic disease, participating in activities that let them feel that they are normal; such activities included going to school, making and being with friends, and playing sports, among others (Wise, 2002). These behaviors were also found in this study with PRHPA. Striving to live a normal life was for some PRHPA about being flexible (about the time) with taking their medications so that they can be normal, and even to sometimes stop taking them. This also was found in studies done with adolescents with other chronic diseases (Admi, 1996; Atkin, & Ahmad, 2001; Christian, & D’Auria, 1997; Hokkanen, Eriksson, Ahonen, & Salantera, 2004; Huus, & Enskar, 2007; Wise, 2002).

The core category of normal, with its descriptions and properties was similar to the findings in a study done with adolescents with cystic fibrosis (Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). In this study, four forms of normalcy were identified. First was “normal to self”, which it was about “To me this is normal”. It was about routinized activities associated with their condition. In PRHPA this “normal to self” was self-identified by almost all
the participants. The establishment of a routine to take their medications and seeing it as normal is part of this form of normalcy (Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). Second, was “normal for (to) self” was about keeping their own personal perceptions of their own normality. It was about not stopping one’s self from achieving one’s goals or aspirations and acting in ways that allowed them to feel that they are not different from how they would have been if they had not had the chronic disease (Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). For PRHPA, HIV does not stop them from doing activities appropriate to their age. Examples were: playing basketball or Playstation, hanging out with friends, and going to sleepovers, among other activities.

Third, “normal to others” was about the adolescent wanting other people to see him/her as normal and wanting to appear similar to others (Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). Some PRHPA did not want to take their medications in front of others because their friends do not take medications. One adolescent female who had special school privileges did not want to use them most of the time, because she wanted to be treated like her classmates. Fourth was “normal to others”. This was about doing things so that the others would think that the adolescent is normal. It was about keeping a conventional normality for an audience which in this case was the friends and peers (Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). In this study PRHPA did activities so that others could see them as normal. An example was when being in activities with friends.

The BSP found in this study, Striving to Live a Normal Life, is about how difficult living with HIV is for these adolescents. These PRHPA are dependent on their medications to stay free of complications. Although they have the knowledge of the consequences of not taking their
ARV medications, they still do not adhere properly and this can be seen as an expression of the need for autonomy and being normal. The use of ways of dealing can also be considered as normalization strategies to try to live a normal life despite the demands of living with HIV and its treatment.

Research Question #2: What factors influence medication adherence (or nonadherence) among HIV positive adolescents?

As was noted in chapter 4, being responsible for taking their medications, the participants said, allowed them to make the decision to take the medications or not. Most of them, 11 out of 13, admitted to not taking the medications sometimes. For some the fear of rejection and stigma made them take the medications at home most of the time or not taking them if they are away from home. They know the consequences of not taking them as prescribed, they want to live, but they still do not take them properly.

First the factors that influence nonadherence in PRHPA will be discussed and then those that influence adherence. The factors that influence medication nonadherence were about what interfered in the life of these PRHPA that kept them from taking their ARV medications. These factors interfered with them taking their medications at the correct time on a certain day or for several days and even months. They have some knowledge but it seems they haven’t internalized the information, so these patterns of medication taking, medication beliefs, are considered to be part of the basic social process of striving to live a normal life. Not taking their medications is seen to be as normal as taking them. The factors they identified that influence medication nonadherence can be classified as patient related, and treatment related. Patient related factors included the fear of rejection and stigmatization, forgetfulness, not wanting to take the
medications in front of their friends, getting tired of taking them, changes in routine, getting bored with taking them, being out in the streets with peers, staying out of their house for the night or weekend, and doing something else. Treatment related factors included being out of medications and bad taste.

The literature is extensive regarding this topic. The study of factors that influence adherence or nonadherence in HIV-positive adolescents has been researched since the 1990s. One of the most common predictors of nonadherence identified in the literature was patient forgetfulness or not remembering to take medications (Belzer, Fuchs, Luftman & Tucker, 1999; Byrne, Honig, Jurgrau, Heffernan, & Donahue, 2002; Van Es, et al., 1998; Waters, Radley-Smith, & Sensky, 2006). Among other factors found that predicted nonadherence were taste and forgetting (Byrne, Honig, Jurgrau, Heffernan, & Donahue, 2002; Gibb, et al., 2003). Adolescents who do not link taking medications with regular daily activities often have difficulties remembering to take their medications (Hosek, Harper, & Domanico, 2005; Murphy, et al., 2003). Medication that had to be taken in the morning was problematic for some adolescents because they were rushing to get to school. Similarly, holidays and other temporary life changes resulted in forgetfulness for some adolescents (Buston, & Wood, 2000). As was said previously, for these PRHPA, a change in their routine like rushing to get to work or school was identified as a factor that influenced nonadherence. Forgetfulness and not wanting to take the medications in front of their friends or in another house, if they were having a sleepover were also factors that influenced nonadherence. HIV-positive adolescents tend to have less structured and more chaotic schedules than adults, with both school and work. This makes adherence more challenging and difficult (Koenig, & Bachanas, 2006). In studies done concerning adherence in HIV-positive
adolescents, reasons for nonadhering properly were forgetfulness, a change in daily routine, busy with other things and slept through the time for the dose (Belzer, Fuchs, Luftman & Tucker, 1999; Murphy, Sarr, Durako, Moscicki, Wilson, & Muenz, 2003). Therefore the findings in the current study were supported by these studies.

The fear of being stigmatized was a factor identified that influenced nonadherence. In this study, PRHPA considered their friends’ support and acceptance to be very important, the fear of being stigmatized and/or rejected made them not tell their friends about their HIV status. Sometimes they coped with their HIV alone to avoid these fears. Stigma was found to predict nonadherence in studies with HIV-positive adolescents (Bikaako-Kajura, et al., 2006; Byrne, Honig, Jurgrau, Hefferman, & Donahue, 2002; Gibb, et al., 2003). Because of the stigma that still exists around HIV, HIV-positive adolescents preferred to keep their HIV status secret, which made it difficult to take medications in the presence of others (Abadia-Barrero, & Castro, 2006; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007).

A treatment regimen can affect an adolescent’s job, school or activities outside the house (Pugatch, Bennett, & Patterson, 2002). Some adolescents felt that instructions on how to take the pills and the schedule were too strict, interfered with their lifestyle or disrupted their social routines (Belzer, et al., 1999; Goode, McMaugh, Crisp, & Wales, 2003; Van Dyke, et al., 2002; Veinot, et al., 2006). The characteristics of the pills, such as taste, influenced nonadherence (Hosek, Harper, & Domanico, 2005; Rosina, Crisp & Steinbeck, 2003).

The factors that influence medication adherence were identified as: family related, health care provider related, patient related and treatment related. The family related factor was about the support that PRHPA receive from their family. The health care provider factor related to
adherence was also the perceived support. In patient related factors, friends’ support, having future plans, a desire to live, being responsible, and disclosure of HIV status to the adolescents were identified. Treatment related factors were about having HIV and medication knowledge, and the establishment of daily routines to take their medications.

Previous research supports this view. For example, family plays an important role in adherence. Research indicates that family support, communication between family members, parental involvement, disclosure of HIV status to children and a healthy parental relationship were determinants of adherence (Bikaako-Kajura, et al., 2006; Ellis, et al., 2007; Kyngas, 2000; Martínez, et al., 2000; Merzel, VanDevanter, & Irvine, 2008; Pugatch, Bennett, & Patterson, 2002; Zindani, Streetman, Streetman, & Nasr, 2006).

As it was found in this research with PRHPA, a variety of studies have shown the importance of both the patient/provider relationship and patient/provider communication on achieving adequate adherence among adolescents with chronic illnesses (Kyngas, 2000; Kyngas, Hentinen, & Barlow, 1998; Merzel, VanDevanter, & Irvine, 2008; Pugatch, Bennett, & Patterson, 2002). These studies all reported that supportive and effective communication was important for helping adolescents understand their disease and treatment, and for improving self-efficacy. Other studies found that disclosing HIV status to the child, having knowledge about the treatment regimen along with HIV knowledge, predicted adherence among children and adolescents with HIV (Byrne, Honig, Jurgrau, Hefferman, & Donahue, 2002; Murphy, et al., 2005; Pugatch, Bennett, & Patterson, 2002; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007).
Research Question #3: What behaviors indicate that the HIV positive adolescents adhere or do not adhere to their prescribed medications?

Although this research question was proposed since the beginning of this study, after collecting and analyzing the data it can be say that this question could not be answered with the data collected and analyzed. The findings did not indicated specific behaviors. It is recommended that further studies should be done with this population in order to obtain an appropriate answer for this research question.

Relation to the Theoretical Framework

This study was based on the theoretical framework of Autonomy Development in the Adolescence of Steinberg (Steinberg, 2005). Autonomy can be defined as a state of being independent or self-governing (Spear & Kulbok, 2004). Growing to independence apart from the family is part of autonomy. Emotional, behavioral and value autonomy encompass the entire process of reaching autonomy during adolescence (Steinberg, 2005).

Emotional autonomy deals with the adolescent as an individual and with his/her relationships, especially with the parents. The process of detachment and individuation are important in acquiring emotional autonomy (Collins & Laursen, 2004; Steinberg, 2005).

Behavioral autonomy refers to self-governance, regulation of one’s own behavior and acting on personal and independent decisions. Decision making ability, peer influence susceptibility, and self – reliance is important tasks to the development of behavioral autonomy (Steinberg, 2005).

Value autonomy has to do with having independent attitudes and beliefs regarding spirituality, politics, ideology and morals. An adolescent’s ability to think in the abstract helps him/her see the differences between general and specific situations, and to make judgments using higher-
level thinking (Steinberg, 2005; Steinberg & Scott, 2003). The development of emotional and behavioral autonomy occurs during early and middle adolescence, while value autonomy develops during late adolescence (Steinberg, 2005).

Having a chronic disease during adolescence constitutes a major challenge for the adolescent, and it can affect psychological development (Suris, Michaud & Viner, 2004). In this study, PRHPA have had the challenge of facing and living every day with HIV. The establishing of coping strategies to deal with HIV is proof of what this population goes through every day and with the developing of autonomy.

In chronic illness, autonomy development may be related to illness control. For some adolescents, having a chronic illness can result in increased independence and increased illness management, which results in the development of autonomy. Chronic illness can increase autonomy issues because of strict treatment regimens. Non adherence can be seen as an emotional issue, of gaining independence and freedom (Dashiff & Bartolucci, 2002). Throughout the interviews it was seen that these PRHPA, besides struggling to live a normal life with HIV, were also struggling to develop autonomy. Adopting and establishing routines in order to take their medications, going to their clinical appointments by themselves and making decisions to adhere or not adhere in some situations were among some the activities that helped them in the process of developing autonomy.

Few studies have found that autonomy was less developed or that there were no differences in the development of autonomy in adolescents with chronic illness (Dashiff & Bartolucci, 2002; Litt, Cuskey & Rosenberg, 1982; Monsen, 1992; Murtaugh & Zetlin, 1990). HIV-positive adolescents may have been isolated from their peers, may have been forced to keep
family secrets including their own HIV status, and may have undergone repeated hospitalizations. Others have experienced family loss and have not had the sustained care of a loving family (Smith-Rogers, 2006). These experiences make it difficult for an adolescent to reach autonomy as part of his/her developmental stage.

This study revealed that the PRHPA have experienced the loss of one or both parents. Also, they have had situations in which they have been forced to not disclose their status, or keep secrets concerning their diagnosis from a family member or friends. This has provided them at time with a feeling of loneliness and depression. This can affect the autonomy development of this population. Although it was not measured or studied in this qualitative research, it can be said that for this population autonomy development is probably more difficult to reach than for those without HIV. Further research on this topic is needed in order to provide a more comprehensive and holistic approach to care.

Implications for Nursing

*Implications for Nursing Research*

Grounded theory methodology provided the substantive theory of medication adherence in PRHPA, *Striving to Live a Normal Life*. The findings of this study can be considered as the beginning of an understanding of the concept of normalcy in this population and how the behaviors of adherence or nonadherence are both seen as normality. Only one study was found in the literature that also identified the concept of normality in HIV-positive adolescents.

Because of the discovery of more effective ARV medications, babies born HIV-positive are living to be adolescents. There is an imperative necessity to perform qualitative studies that add to the body of knowledge of nursing concerning the adolescent’s experiences and/or
meanings of living a normal life with HIV and of having to adhere to their medications in order to prolong their lives.

Also, a concept analysis of normalcy using adolescents with chronic diseases will add to the body of knowledge a more extensive understanding of this concept and provide with some guidance that can help in the development of an instrument that can measure normality in this population. This can also provide evidence to support the creation of interventional programs that will help this population live a normal life with HIV.

**Implications for Nursing Theory**

The findings of this study expand and add some support to most of the studies done previously, where the concepts of normal, normalcy or normalization were identified when adolescents with chronic diseases were the participants. It is the beginning of understanding the behavior of medication adherence relate to these concepts in HIV-positive adolescents.

For nursing theory, these findings provide the basis for and the beginning of the development of a new body of knowledge in nursing. The knowledge of the experiences of HIV-positive adolescents living a normal life with HIV and how living a normal life affects their adherence to their medications can be said to be new. If nursing wants to expand its body of knowledge concerning this topic, more studies are imperative in which the results can help in the developing of a middle range theory that can be called “Theory of Normalcy in Adolescents with Chronic Disease.”

**Implications for Nursing Practice**

The findings of this study imply that health care providers to this population, especially nurses, have to be aware of and understand that these HIV-positive adolescents are struggling to
live a normal life and how adhering to their medications, or not, affects their normal life. It also supports the importance of defining and describing the concept of normality and the engagement of normalization strategies as a consequence of striving to live a normal life.

The complexity of these findings suggests, besides the need for more studies, the creation of interventional programs. These programs will have to be implemented with psychosocial support included, a holistic approach and concentrated on providing, among other things, healthy and positive interventions in order to help them live their life as normally as possible.

Because they are at evolving maturity levels during their adolescence, it is necessary to identify interventions appropriate to their level of maturity. Also, it is important to individualize these interventions and to take special consideration of the cultural context involved here. Because adolescents are searching for autonomy, interventions that encourage independence should be included in their care plans.

To address PRHPA problems with medication adherence the creation of support groups where the members are PRHPA can help because they can talk about their secrets, dealing with how to tell friends, how they feel about keeping the secret or hiding to take the medications. Also they can talk about sex and ways of dealing with HIV in an everyday basis. Another intervention can be the creation of pamphlets or DVDs where the topic of “living with HIV as a Puerto Rican HIV-positive adolescent” is discussed.

**Strengths of the Study**

One of the strength of this study is in that the findings provide a basis for understanding the concept of living a normal life among PRHPA and the behavior of medication adherence. These findings are the beginning of an understanding and the creation of a new body of
knowledge concerning this population. It is expected that the publication of the results of this study will provide an initiative for nurses to perform further investigations concerning this topic. This study’s findings support the findings in a study done with HIV-positive adolescents from France in which the concept of normality related to their lives was also identified. This was the only study found concerning this topic and with this population.

Second, some of the findings of this study support the findings of previous studies done with HIV adolescents. Among those findings are that most of the PRHPA have lost one or both parents of AIDS and live with blood related family members. Another supportive finding were the factors identified that influence adherence and nonadherence are similar to those identified in other studies and finally that the fear of rejection and being stigmatized are still seen as having potential social consequences, therefore most of this population keeps their HIV status a secret.

Limitations of the Study

There were several limitations which should be noted, including some logistical difficulties with recruitment and the researcher’s own inexperience with research interviews with this age group.

The recruitment of the participants was a limitation for several reasons. First, some of them drive and are responsible for their treatment regimen. This means that their legal guardian, most of the time does not go with them to the clinic. There were days that PRHPA, who could recruit for the study, could not participate because their legal guardian was not there to sign the consents. Second, on at least in 4 occasions the researcher went to the clinic and potential participants did not attend to the clinic because of living far away and not having enough money for transportation and food.
Third, the researcher was not able to recruit HIV-positive adolescents for whom the PR Family Department is the legal guardian. The reason was that these adolescents are minors and it was necessary to get the consent of their legal guardian. Having the PR Family Department as legal guardian made the recruitment difficult because of all the rules and regulations needing to be fulfilled in order for them to consent.

The researcher’s limited experience as an interviewer was another limitation. Interviewing adolescents is not easy. It is a challenge. Although many readings and some practices were done before the interviews started, being there was different than the practice. For example, although she brought a card to remind her to do one question at a time, sometimes she found herself asking more than one question simultaneously. This brought confusion several times to the adolescent.

The use of only one clinic limited the participation of other HIV-positive adolescents that receive health care in other health care scenarios. Using one setting represents a sample and not the entire spectrum of the population of HIV-positive adolescents in Puerto Rico. The use of other clinics might have produced different data.

Recommendations for Future Research

The findings of this study clearly demonstrated that PRHPA have different perceptions, each other, about living with HIV. There is a possibility that other variables could have played a major role in explaining these differences. Future research concerning this population is imperative. Research done on HIV-positive adolescents in the world is scarce and in Puerto Rico is no exception. The results of this study indicated that PRHPA’s life is complicated. More
studies are needed concerning this population to relate the findings of other similar studies done with the same population but from other countries.

Concepts such as stigma, quality of life, quality of care and, normalcy, among others should be studied in with this population and relation to adherence and nonadherence. Studying the family’s perception, experiences and/or meaning of having an HIV-positive adolescent at home will provide more insights of the complex behavior of adherence in PRHPA. Exploring the experiences, perceptions and/or meaning of the health care providers by this population will help to have a better understanding of adherence by this population that receive care from them. Finally, exploring the social processes and cultural particularities of the concept of normality using these PRHPA will provide value knowledge that can help in the creation of interventional tailored made program that will enhance adherence.

Summary

This chapter started by presenting the answers to the three research questions proposed for this study. After each question was answered it was discussed and related to the literature. This presentation was followed by a discussion of the theoretical framework with the findings. Discussion of the implications of the study findings with nursing research, theory and practice followed. The chapter concluded presenting the strength and limitations of the study and the recommendations for future research.
APPENDIX A: UNIVERSITY OF ARIZONA – HUMAN SUBJECTS PROTECTION

COMMITTEE APPROVAL LETTER
09 February 2009

Juan Rodriguez, PhD Student
Advisor: Elaine Jones, PhD
Nursing
PO Box 210203

RE: PROJECT NO. 08-0099-02 Medication Adherence in HIV-Positive Adolescents Living in Puerto Rico: A Qualitative Study

Dear Ms. Rodriguez,

The IRB Committee reviewed your 23 January 2009 letter and revised Minor Assent Form for participants age 15, 16, 17; the Spanish translations of the revised Minor Assent Form; and the Spanish translation of the Informed Consent Form for participants ages 18 or 19; and a copy of the IRB approval from Puerto Rico for the above referenced project at the convened meeting of 09 February 2009. All of the conditions as set out in Committee's 14 January 2009 letter (relevant to the 12 January 2009 Full Board review) were addressed in the investigator's 23 January 2009 letter and the accompanying submitted revised materials, additionally, minor administrative changes to the Subject's Consent Form were made as requested by Committee and re-submitted as version 02/03/09. Therefore, approval for this project-at-risk project is granted with an expiration date of 08 February 2010.

Please make copies of the attached IRB stamped consent documents to consent your subjects. Note that approval of this project also includes the following documents: Informed Consent for participants ages 18 or 19: Spanish translation of the Informed Consent for participants ages 18 or 19; Spanish translation of the Informed Consent Form for participants ages 18 or 19; Parent/Legal Guardian Permission Form version December 3, 2008; Spanish translation of Parent/Legal Guardian Permission Form version December 3, 2008; Minor Assent Form for participants ages 15, 16, 17 revised 02/03/09; and the Spanish translation of the Minor Assent Form for the participants ages 15, 16, 17.

In accordance with 45 CFR 46.408(b) and 21 CFR 50.54(e)(1), the IRB has determined that permission of one parent is sufficient as it is research involving and greater than minimal risk as defined in 45 CFR 46.404.

The Institutional Review Board (IRB) of the University of Arizona has a current Federally Approved Assurance of compliance, FWA00004218, which is on file with the Department of Health and Human Services and covers this activity.

Approval is granted with the understanding that no further changes or additions will be made to the procedures followed or the consent forms used (copies of which we have on file) without the knowledge and approval of the Institutional Review Board. Any research related physical or psychological harm to any subject must also be reported to the appropriate committee.
APPENDIX B: UNIVERSITY OF PUERTO RICO – MEDICAL SCIENCES CAMPUS

HUMAN SUBJECTS PROTECTION COMMITTEE APPROVAL LETTER
Date: October 22, 2008

Protocol Number: A2230109

Principal Investigator: Janet Rodríguez

Department / Division: School of Nursing

Sponsor:

Title: Medication Adherence in HIV Positive Adolescents Living in Puerto Rico: A qualitative study

Thank you for your response to requests from a prior review of your application. This type of response qualifies for expedite review under FDA and OHRP regulations. This is to confirm that your application is now fully approved.

This action involves:
- New protocol/project
- Waiver of Consents
- Continuing Review of Previously Approved Protocol
- Protocol Amendment

The following documents were reviewed under this submission:
- Protocol
- Assent Document
- Informed Consent Document
- Letter of Amendment
- Survey Instrument
- Package Insert
- Advertisement
- Human Subject Certified

In compliance with federal regulations the approval for this study is valid through September 24, 2009. For additional information please contact Human Research Subjects Protection Office at 787-225-0010 or 787-225-0016, e-mail orph@cmn.upr.edu.

Cordially,

[Signature]

Martha Iriarte
Chairperson, IRB
Date: September 28, 2009
Protocol Number: A2230109
Principal Investigator: Janet Rodriguez
Department / Division: School of Nursing
Sponsor:
Title: Medication Adherence in HIV Positive Adolescents Living in Puerto Rico: A qualitative study

This is to certify that the above referenced research proposal/protocol was evaluated on September 28, 2009 and meets expedite IRB review category. The research proposal was approved. A progress report (continuous review) is due in one year and/or at the end of the study.

This action involves:
- New proposal/project
- Waiver of Consents
- Continuing Review #1 of Previously Approved Protocol
- Protocol Amendment #
- Amendment #
- Adverse Events
- Serious Adverse Events
- Enrollment Closed
- Data Analysis
- Followup
- Authorization Letter
- Letter to Participants
- Informational Sheet
- New Study Personnel
- FDA #572
- Progress Report
- Site Visit Report
- Letter of Amendment
- Audit Report
- HIPAA Identifiers
- Others

The following documents were reviewed under this submission:
- Protocol
- Abstract
- Assent Document
- Informed Consent Document
- Letter of Amendment
- Survey Instrument
- Package Insert
- Advertisement
- Human Subject Certified
- Curriculum Vitae
- HIPAA Certified
- Investigator Brochure

In compliance with federal regulations, the approval for this study is valid through: September 27, 2010.
For additional information please contact Human Research Subjects Protection Office at 787-282-0010 or 787-282-0018; e-mail oppni.crm@upr.edu.

Cordially,

[Signature]
Luis M. Muniz, EDO
Chairperson IRB 3

1. Research must be conducted according to the proposal that was approved by the IRB.
2. Changes to the protocol or its related consent document must be approved by the IRB prior to implementation.
3. All serious or unexpected adverse events/drug reactions should be reported.
4. Each subject should receive a copy of the consent document, if appropriate.
5. Records must be retained for at least three years.
6. Any future correspondence should include the IRB identification number provided and the study title.
APPENDIX C: LETTER OF APPROVAL AND COLLABORATIVE AGREEMENT OF
GAMMA IMMUNOLOGY CLINIC
COLLABORATION AGREEMENT

This document represents a collaborative agreement between Janet Rodriguez, RN, MSN, Principal Investigator and an Associate Professor of the University of Puerto Rico, Medical Sciences Campus, School of Nursing and the Pediatric Research Center of the University of Puerto Rico, Medical Sciences Campus, School of Medicine, and Pediatric Department for the period of September 2008 to May 2009.

Purpose: This serves to assure the effectiveness of activities directed to the development of a research titled: Medication Adherence in HIV – Positive Adolescents Living in Puerto Rico: A Qualitative Study.

In specific reference to the research titled Medication Adherence in HIV – Positive Adolescents Living in Puerto Rico: A Qualitative Study the Pediatric Research Center agrees to provide the following:

- Identification and access of their HIV/AIDS infected clientele that meet the criteria for inclusion into the research.
- The referral of potential participants
- Provide access to physical space that permits privacy for the interview and data collection process
This document represents a collaborative agreement between Janet Rodriguez, RN, MSN, Principal Investigator and an Associate Professor of the University of Puerto Rico. Medical Sciences Campus, School of Nursing and the Pediatric Research Center (the University of Puerto Rico. Medical Sciences Campus. School of Medicine. and Pediatric Department for the period of September 2008 to May 2009.

Purpose: This serves to assure the effectiveness of activities directed to the development of a research titled: Medication Adherence in HIV - Positive Adolescents living in Puerto Rico: A Qualitative Study

In specific reference to the research titled Medication Adherence in HIV - Positive Adolescents living in Puerto Rico: A Qualitative Study the Pediatric Research Center agrees to provide the following:

- Identification and access of their HIV/AIDS infected clientele that meet the criteria for inclusion into the research.
- The referral of potential participants.
- Provide access to physical space that permits privacy for the interview and data collection Process.
In specific reference to the dissertation research *Mediation Adherence HIV - Positive Adolescents living in Puerto Rico: A Qualitative Study*, the Principal Investigator Janet Rodriguez, MSN, FNP agrees to provide the following:

- A written copy of the results of the research so that this information may be used by the organization.

**Indemnity:**

This agreement does not represent a legal obligation between parties, but, a good faith agreement that formalizes and alliance to increase research effectiveness and availability of HIV/AIDS specific services to the people that receive said services.

**Responsibility:**

The following persons are authorized representatives and agree to comply with the mentioned statements. Both parties also agree to comply with the confidentiality and privacy statutes stated by law.

______________________________  ________________________
Irma Febo, MD.                          Date
Director
Pediatric Research Center
University of Puerto Rico - Medical Sciences Campus
School of Medicine - Pediatric Department

_______________________________  __________________________
Janet Rodríguez, MSN, FNP                              Date
Principal Investigator
Associate Professor
University of Puerto Rico - Medical Sciences Campus
School of Nursing
APPENDIX D: CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY (IN SPANISH AND APPROVED BY THE UPR-MSC IRB) HOJA DE CONSENTIMIENTO PARA PARTICIPAR EN UN ESTUDIO DE INVESTIGACION
HOJA DE CONSENTIMIENTO PARA PARTICIPAR EN UN ESTUDIO DE INVESTIGACIÓN

TITULO: Adherencia a Medicamentos en Adolescentes VIH Positivo
Que viven en Puerto Rico: Una Investigación Cualitativa

INVESTIGADOR PRINCIPAL: Janet Rodríguez, MSN, FNP.

LUGAR: Clínica GAMMA de la Universidad de Puerto Rico-Recinto de Ciencias Médicas – Escuela de Medicina

NÚMEROS DEL TELÉFONO: (787) 754-5655; 754-5659

Esta hoja de consentimiento puede contener palabras que usted no entienda. Por favor pregunte al investigador encargado para que le explique cualquier palabra o información que usted no entienda claramente. Usted puede llevarse a su casa una copia de este consentimiento para pensar sobre este estudio o para discutir con su familia o amigos antes de tomar su decisión.

I- INTRODUCCION:
Usted/su hijo(a) ha sido invitado a participar en este estudio de investigación. Antes de que usted y su hijo(a) decidan participar en este estudio por favor lea este consentimiento cuidadosamente. Haga todas las preguntas que usted tenga, para asegurarse de que entienda los procedimientos del estudio, incluyendo los riesgos y los beneficios.

II- PROPOSITO DEL ESTUDIO:
De acuerdo con el Departamento de Salud, para Enero del 2008 había en PR 258 casos de VIH entre las edades de 10 a 19 años y 224 casos de SIDA entre las edades de 13 a 19 años. En un estudio realizado en PR con adolescentes VIH positivo se encontró que el por ciento de tomarse los medicamentos para el VIH está entre el 17% al 100%. Se hace necesario llevar a cabo investigaciones para diseñar intervenciones y mejorar este problema de incumplimiento en tomarse los medicamentos para el VIH en PR.

El propósito de este estudio es describir el proceso social por el cual los adolescentes VIH positivo se toman los medicamentos para su enfermedad; identificar los factores que influencian el tomarse o no los medicamentos para el VIH; e identificar que comportamientos indican que el adolescente VIH positivo se está tomando o no sus medicamentos.
III- PARTICIPANTES DEL ESTUDIO:

¿Quién puede formar parte de este estudio?

1. Adolescentes VIH positivo o con SIDA
2. Tener entre 15 a 19 años de edad
3. Estar recibiendo tratamiento de medicamentos para el VIH o SIDA
4. Poder hablar español o inglés
5. Estar dispuestos(as) a participar de una entrevista, que será grabada y pasada a escrito, con la investigadora principal.

No podrán participar las siguientes personas:

1. Adolescentes que no sean VIH positivo o no tengan SIDA
2. Menores de 15 años y mayores de 19 años
3. Que no estén recibiendo tratamiento para el VIH o SIDA
4. Que no puedan hablar en español ni en inglés
5. Que no estén dispuestos a participar en una entrevista que será grabada con la investigadora principal.

El estudio es completamente voluntario. Usted puede abandonar el estudio en cualquier momento sin ser penalizado ni perder los beneficios.

¿Cuántas personas se espera que participen en este estudio?
Se espera que en este estudio participen 20 adolescentes VIH positivo.

IV- PROCEDIMIENTO:

¿Qué exactamente me harán en este estudio? ¿Cuáles serán los procedimientos de investigación en los que participare si decido entrar en el estudio?

A usted se le va a pedir lo siguiente:

1. Que lea, haga preguntas si tiene dudas y firme este consentimiento informado para la participación en el estudio de investigación.
2. Que el día que venga a participar del estudio debe estar preparado para contestar preguntas en una entrevista de aproximadamente entre 45 minutos y una hora. Dicha entrevista será grabada y transcrita para propósitos de análisis solamente.
3. Que complete un cuestionario, sin identificar su nombre, sobre datos demográficos, edad, años de estudios y grado más alto alcanzado, miembros/as en la familia, ingresos, actividades y hábitos e información de salud.
¿Cuánto tiempo me tomará participar en este estudio?
A usted le tomará aproximadamente entre 45 minutos y 1 hora terminar su participación en este estudio.

**V- RIESGOS O INCOMODIDADES:**

Los riesgos o incomodidades que usted puede tener al participar en este estudio son mínimos. Estos pueden causar un poco de incomodidad o ansiedad al contestar algunas de las preguntas de la entrevista.

**VI- BENEFICIOS:**

Es probable que usted no reciba ningún beneficio personal por participar en este estudio. Su enfermedad, tener el virus de inmunodeficiencia adquirida (VIH positivo), puede mejorar como resultado de su participación en este estudio, aunque no hay garantía de que esto suceda.

La información de este estudio de investigación podría conducir y proveer dirección para desarrollar nuevas intervenciones que ayuden a mejorar el cumplimiento a medicamentos y a su vez esto ayudará a mejorar la calidad de vida de estos adolescentes VIH positivo.

**VII- COSTOS:**

No hay ningún costo por las visitas del estudio.

**VIII- INCENTIVO PARA EL PARTICIPANTE:**

A usted no se le pagará nada por ser parte de este estudio.

**IX- ALTERNATIVAS DE TRATAMIENTO:**

Su participación en este estudio es voluntaria. Usted puede decidir no participar en este estudio. Si usted decide que no va a participar o que va a retirarse antes de completar el estudio, esta decisión no representa ninguna penalidad en el servicio que se le ofrece la clínica de GAMMA.
X- PRIVACIDAD Y CONFIDENCIALIDAD:

Si usted elige estar en este estudio, el investigador principal del estudio conseguirá información personal sobre usted. Esto puede que incluya la información que pueda identificarle a usted. El investigador principal puede también conseguir información sobre la salud suya incluyendo: expedientes médicos de ahora; e información obtenida durante este estudio sobre su enfermedad del VIH o SIDA.

Los resultados de esta investigación pueden ser publicados en revistas científicas o ser presentadas en las reuniones de profesionales de la salud, pero la identidad suya no será divulgada. La información de salud suya será mantenida tan confidencial como sea posible bajo la ley.

La información puede ser revisada por el Comité de Derechos Humanos (IRB, siglas en ingles) de la Universidad de Puerto Rico, Recinto de Ciencias Médicas. El IRB del RCM es un grupo de personas quienes realizarán la revisión independiente de la investigación según los requisitos de las regulaciones.

Todo el material de este estudio, incluyendo el cuestionario demográfico y las transcripciones se guardaran en un armario que tiene llave. Esta llave la tendrá solamente la Investigadora Principal del estudio, la Sra. Janet Rodríguez. Las cintas de las grabaciones serán destruidas una vez se verifique que la transcripción realizada de la misma este correctamente hecha. Al cabo de 5 años todo el material de este estudio será destruido con una máquina trituradora de papel.

Esta autorización servirá hasta el final del estudio, a menos que usted la cancele antes. Usted puede cancelar esta autorización en cualquier momento enviando un aviso escrito al Investigador Principal en la siguiente dirección:

Janet Rodríguez, MSN, FNP.
Universidad de Puerto Rico
Recinto de Ciencias Médicas
Escuela de Enfermería
PO Box 365067
San Juan, PR 00936-5067

Si usted cancela esta autorización, el Investigador Principal no usará ni divulgará su información personal ni de salud. Esta información solo se divulgará en caso que se necesite la información personal de su salud para preservar la integridad científica del estudio. La información sometida antes de que usted cancele esta autorización puede ser utilizada para publicar o ser presentada.
La autorización para el uso y acceso de la información protegida de la salud para los propósitos de la investigación es totalmente voluntaria. Sin embargo, de no firmar este documento usted no podrá participar en este estudio. Si en el futuro usted cancela esta autorización, no podrá continuar participando en este estudio.

XI- COMPENSACION EN CASO DE DAÑO:

En caso de lesión física y/o mental como resultado de este estudio, usted recibirá tratamiento médico, libre de costos en el Hospital Pediátrico o cualquier otro hospital designado por el Rector del Recinto de Ciencias Medicas de la Universidad de Puerto Rico.

XII- PARTICIPACION Y RETIRO VOLUNTARIO:

La participación suya en este estudio es voluntaria. Usted puede decidir no participar o retirarse del estudio en cualquier momento. La decisión suya no resultará en ninguna penalidad o pérdida de beneficios para los cuales tenga derecho. De ser necesario, su participación en este estudio puede ser detenida en cualquier momento por el investigador principal del estudio sin su consentimiento.

XIII- FONDOS PARA PAGAR EL ESTUDIO:

Este estudio no recibirá fondos monetarios para llevarse a cabo.

XIV- PREGUNTAS:

Si tiene alguna pregunta sobre este estudio o sobre su participación en el mismo, puede llamar a la Sra. Janet Rodríguez, Investigadora Principal al (787) 754-5655 o al (787) 754-5659.

Si usted tiene alguna pregunta sobre sus derechos como participante del estudio, usted puede llamar a la:

Oficina de Protección de Participantes Humanos en Investigación
Teléfonos: (787) 282-0018; (787) 282-0010
Correo electrónico o email: opphi@rcm.upr.edu

No firme este consentimiento a menos que usted haya tenido la oportunidad de hacer preguntas y recibir contestaciones satisfactorias para todas sus preguntas. Si usted firma aceptando participar en este estudio, recibirá una copia firmada, con el sello de aprobación de IRB y con la fecha de esta hoja de consentimiento para usted.
XV- CONSENTIMIENTO:

He leído la información de esta hoja de consentimiento, o se me ha leído de manera adecuada. Todas mis preguntas sobre el estudio y mi participación han sido atendidas. Yo autorizo el uso y la divulgación de mi información de salud a las entidades antes mencionadas en este consentimiento para los propósitos descritos anteriormente.

Al firmar esta hoja de consentimiento, no se ha renunciado a ninguno de los derechos legales.

_______________________________
Nombre del Participante

_______________________________  _______________________
Firma del Participante  Fecha

_______________________________
Firma del Investigador Principal  Fecha

_______________________________
Nombre del Padre/Madre/Tutor Legal

_______________________________  _______________________
Firma del Padre/Madre/Tutor Legal  Fecha
APPENDIX E: INFORMED CONSENT (PARTICIPANTS AGES 18 OR 19) APPROVED BY UNIVERSITY OF ARIZONA IRB
Informed Consent
(Participants ages 18 or 19)

Project Title: Medication Adherence in HIV Positive Adolescents Living in Puerto Rico: A Qualitative Study

Introduction

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. The Principal Investigator, Mrs. Janet Rodriguez, will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

What is the purpose of this research study?

The purpose of this project is to learn about the process of medication adherence in you as a youth who are HIV positive. In other words, what influences you as an HIV positive youth to take their medications or not?

Why are you being asked to participate?

You are being invited because you are:
1) between 18 or 19 years of age
2) are HIV positive or have AIDS
3) can speak Spanish or English
4) are able to participate in an audiotape interview for 45-60 minutes.
5) are receiving care for HIV/AIDS at GAMMA clinic

How many people will be asked to participate in this study?

Approximately 20 adolescents who are HIV positive will be asked to participate in this study. Some will be 18-19 years old, and others will be between 15-17 years old.

What will happen during this study?

The PI (Mrs. Rodriguez) will make an appointment with you for an interview. You will also be asked some information about yourself, such as your age and who lives with you. You will be asked to choose a fake name to use during the interview. The interview will be conducted in either English or Spanish (whichever you prefer), and it will be audiotaped, if you give permission. Examples of questions to be asked are: Tell me about when you found out that you have HIV. Thinking back on your experience, how has your life changed since you knew that you have HIV? What happened after you learned you had

Version: Page 1 of 4 Participant’s Initials
HIV? (Prompt: who did you talk to? Where did you go for care? What treatment were you given?)

**How long will I be in this study?**

About 45-60 minutes

**Are there any risks to me?**

The things that you will be doing have minimal risk. You might feel upset when you are talking about your experiences and sharing sensitive information. If this occurs you can stop participating immediately, and The PI will recommend that you seek care from the clinic staff where you are being treated for HIV/AIDS.

**Are there any benefits to me?**

You will not receive any direct benefit from taking part in this study. However, you may feel some satisfaction from sharing your experiences and knowing that the information you share may be useful in improving care of other youth with HIV/AIDS in the future.

**Will there be any costs to me?**

Aside from your time, there are no costs for taking part in the study.

**Will I be paid to participate in the study?**

You will not be paid for your participation.

**Will video or audio recordings be made of me during the study?**

We will make an audio recording during the study so that we can be certain that your responses are recorded accurately only if you check the box below:

- [ ] I give my permission for audio recordings to be made of me during my participation in this research study.

- [ ] I do not give my permission for audio recordings to be made of me during my participation in this research study.

**Will the information that is obtained from me be kept confidential?**

The only persons who will know that you participated in this study will be the Principal Investigator. The data collected from this study, including the audiotapes and transcriptions will be confidential. You will not be identified by your real name in any
reports or publications resulting from the study. Representatives of regulatory agencies (including The University of Arizona Human Subjects Protection Program) may access your records, without your name on them.

**What if I am harmed by the study procedures?**

There are no known risks of physical harm by participating in the study.

**May I change my mind about participating?**

Your participation in this study is voluntary. You may change your mind about being in the study at any time. If you decide not to be in the study, it will have no effect on the care you receive from the GAMMA Clinic.

**Whom can I contact for additional information?**

You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator Janet Rodriguez, MSN, FNP at (787) 754-5655.

If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can’t reach the research team, or want to talk to someone other than the research team, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web, please visit the following website: http://www.irb.arizona.edu/contact/.

**Your Signature** By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

______________________________
Name (Printed)

______________________________            __________________________
Participant's Signature            Date signed

**Statement by person obtaining consent** I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits

Version:        Page 3 of 4        Participant's Initials
associated with participation in this study. Any questions raised have been answered to the participant's satisfaction. Name of the Principal Investigator

Principal Investigator Signature ___________________________ Date signed ____________

Version: ___________________________ Page 4 of 4 _____________ Participant's Initials ______
APPENDIX F: CONSENTIMIENTO INFORMADO (PARTICIPANTES EDAD DE 18 A 19 AÑOS) APPROVED BY UNIVERSITY OF ARIZONA IRB
Consentimiento Informado
(Participantes edad de 18 a 19 años)

Título del Proyecto: Adherencia a Medicamentos en Adolescentes VIH Positivos que Viven en Puerto Rico: Un Estudio Cualitativo

Introducción

Usted ha sido invitado a participar en un estudio de investigación. La información que se provee en este consentimiento te ayudará a tomar una decisión sobre si quieres participar o no. La Investigadora Principal (IP), Sra. Janet Rodríguez, MSN, FNP estará disponible para contestar todas las preguntas que tengas y proveerte información adicional si es necesario. Se te dará una copia de este consentimiento informado luego de firmarlo.

¿Cuál es el propósito de este estudio de investigación?

El propósito de este proyecto es para aprender sobre tu proceso de cómo te adhieres a tus medicamentos como un joven con VIH. En otras palabras, que te influencia como un joven con VIH a tomar o no tus medicamentos?

¿Por qué se le está preguntando a usted que participe?

Usted ha sido invitado porque:

1) estás entre la edad de 18 y 19 años 
2) eres VIH positivo o tienes SIDA 
3) puedes hablar español o inglés 
4) estás capacitado para participar en una entrevista que será grabada y durará entre 45 a 60 minutos 
5) estás recibiendo cuidados para el VIH/SIDA en la Clínica de GAMMA

¿A cuántas personas se les preguntará que participe en este estudio?

Aproximadamente 20 adolescentes que son VIH positivo se le preguntará que participe en este estudio. Algunos tendrán entre 18 y 19 años y otros entre 15 a 17 años.

¿Qué pasará durante el estudio?

La IP (Sra. Rodríguez) hará una cita con usted para una entrevista. A usted además se le preguntará información sobre usted, tales como, la edad y con quien vives. Se le dirá que elija un nombre ficticio para ser utilizado durante la entrevista. La entrevista será realizada en español o en inglés, como usted prefiera y será grabada si usted da el permiso. Ejemplos de preguntas a ser realizadas son: Cuéntame cuando te dijeron que tenías VIH, Pensando en el pasado sobre esa experiencia, cómo tu vida ha cambiado desde que sabes que eres VIH positivo? ¿Qué pasó después que supiste que tenías
¿Cuánto tiempo estaré en este estudio?
Aproximadamente de 45 a 60 minutos.

¿Conlleva este estudio algún riesgo para mí?
Las actividades que estarás haciendo durante este estudio conllevan un mínimo de riesgo para ti. Te puedes sentir molesto o triste cuando estés hablando sobre tus experiencias y compartiendo información sensible. Si esto ocurre puedes dejar de participar en este estudio inmediatamente y la IP te recomendará buscar ayuda del personal cualificado de la clínica donde recibes tratamiento para el VIH/SIDA.

¿Hay algún beneficio para mí?
No recibirás ningún beneficio directo por participar en este estudio. Puedes sentir alguna satisfacción de poder compartir tus experiencias y saber que la información que compartas puede ser útil para mejorar el cuidado de otros adolescentes con VIH/SIDA en el futuro.

¿Habrá algún costo en que tengo que incurrir?
Aparte de tu tiempo, no hay ningún otro costo para ti por participar en este estudio.

¿Se me pagará por participar en este estudio?
No se te pagará por participar en este estudio.

¿Durante este estudio, se me realizará algún video o grabación?
Solamente si das el permiso con una marca de cotejo (✓) abajo, se te realizará una grabación de la entrevista durante el estudio para asegurarnos de tus respuestas de forma correcta:

☐ Estoy dando el permiso para que graben mi entrevista durante este estudio.

☐ No estoy dando el permiso para que graben mi entrevista durante este estudio.

¿La información que se obtenga de mí en este estudio, se mantendrá confidencial?
La única persona que sabrá que participaste en este estudio será la IP. Los datos coleccionados en este estudio incluyendo las grabaciones y las transcripciones de las grabaciones será información confidencial. Tú no estarás identificado con tu nombre verdadero en ningún reporte ni publicación que se lleve a cabo sobre este estudio. Representantes de las agencias reguladoras, como la Agencia Reguladora de los Derechos Humanos, puede asesorar tu expediente sin tu nombre en él.

¿Qué tal si me hacen daño durante el estudio?

No exista la posibilidad de daño físico al participar durante este estudio.

¿Puedo cambiar de opinión sobre mi participación en este estudio?

Tu participación en este estudio es voluntaria. Puedes cambiar de opinión sobre tu participación en este estudio en cualquier momento. Si tú decides no participar en este estudio, esta decisión no tendrá ningún efecto en el cuidado que te ofrecen en las clínicas de GAMMA.

¿A quién puedo contactar para información adicional?

Puedes obtener información adicional sobre la investigación, tus dudas o quejas sobre la investigación llamando a la IP, Janet Rodríguez, MSN, FNP al (787) 754-5655.

Si tienes preguntas con respecto a tus derechos como participante o preguntas en general o te gustaría ofrecer tu opinión sobre la investigación y no puedes conseguir a la IP o no deseas hablar con la IP, puedes llamar a la oficina del Programa de Protección de los Sujetos Humanos de la Universidad de Arizona al (520) 626-6721. (Si estas fuera del estado llamar al número libre de cargos al 1-866-278-1455). Si deseas contactar el Programa de Protección de los Sujetos Humanos por vía electrónica, favor de visitar la siguiente página:
http://www.irb.arizona.edu/contact/.

Tú Firma: Al firmar este consentimiento, yo afirmo que he leído la información que ella contiene, que el estudio ha sido explicado a mí, que mis preguntas han sido contestadas y que yo estoy de acuerdo en participar en este estudio. No estoy renunciando a ninguno de mis derechos legales al firmar este consentimiento.

_____ Estoy dando el permiso para grabar la entrevista.

_____ No estoy dando el permiso para grabar la entrevista.

Versión: 3 de diciembre de 2008. Página 3 de 4 Iniciales del Participante_____
Nombre (Impreso)

_______________________________  _______________________
Firma del Participante            Fecha

Oración de la persona que obtiene el consentimiento:

Yo certifico que he explicado este estudio de investigación a la persona que ha acordado participar y que ella o él ha sido informado del propósito, procedimientos, los posibles riesgos y beneficios potenciales asociados con su participación en este estudio. Cualquier pregunta realizada ha sido satisfactoriamente contestada al participante. Janet Rodríguez, MSN, FNP.

_______________________________  _______________________
Firma de la Investigadora Principal Fecha

Versión: 3 de diciembre de 2008.    Página 4 de 4    Iniciales del Participante_____
APPENDIX G: MINOR’S ASSENT FORM (PARTICIPANTS AGES 15, 16 OR 17 YEARS)

APPROVED BY UNIVERSITY OF ARIZONA IRB
MINOR'S CONSENT FORM
(Participants ages 15, 16 or 17 years)

Title of Project: Medication Adherence in HIV Positive Adolescents living in Puerto Rico: A Qualitative Study

Your mother, father or legal guardian has told me it was okay for you to participate in this study. The purpose of this study is to learn more about the experience of youth who are HIV positive, especially with taking medications for HIV/AIDS. If you agree to participate, Mrs. Rodriguez will ask you to pick a fake name to use, you will be interviewed for about 45-60 minutes and you will fill out a questionnaire about yourself. Examples of questions to be asked are: Tell me about when you found out that you have HIV. Thinking back on your experience, how has your life changed since you knew that you have HIV? What happened after you learned you had HIV? (Prompt: who did you talk to? Where did you go for care? What treatment were you given?)

The interview will be conducted in a private office at GAMMA clinic on a day and time convenient for you. There is no charge for being in the study, and you will not be paid for participating. There are minimal risks for being in the study. Perhaps you might feel upset when you are discussing your experiences. If that happens, Mrs. Rodriguez will recommend that you make an appointment with your health care providers at the clinic. Results of this study will be used to improve care for other people your age who also have HIV/AIDS. Your participation is voluntary and you can change your mind anytime without any hard feelings, and it will not have any effect on the care you receive from the clinic.

Do you have any questions? Are you willing to participate in this study?

Youth's Name

Youth’s Signature Date

Investigator’s Signature Date

Version Date: 2/3/09 Revised Parent/Legal Guardian Initials
APPENDIX H: FORMATO DE ASENTIMIENTO A MENORES (PARTICIPANTES ENTRE 15 A 17 AÑOS) APPROVED BY UNIVERSITY OF ARIZONA IRB
Formato de Asentimiento a Menores
(Participantes entre 15 a 17 años)

Título del Proyecto: **Adherencia a Medicamentos en Adolescentes VIH Positivos que Viven en Puerto Rico: Un Estudio Cualitativo**

Tu madre, padre o tutor legal, me ha informado que está de acuerdo en que tú participes en este estudio. El propósito de este estudio es para aprender sobre tu proceso de cómo te adhieres a tus medicamentos como un joven con VIH/SIDA. Si decides participar, la Sra. Rodríguez te preguntará que elijas un nombre ficticio para usarlo durante el estudio, serás entrevistado por aproximadamente 45 a 60 minutos y llenarás un cuestionario sobre ti mismo. Ejemplos de preguntas a ser realizadas son: Cuántame cuando te dijeron que tenías VIH; Pensando en el pasado sobre esa experiencia, como tu vida ha cambiado desde que sabes que eres VIH positivo? ¿Qué pasó después que supiste que tenías VIH? ¿(¿Con quién hablaste? ¿Dónde fuiste para recibir cuidado? ¿Qué tratamiento te dieron?)

La entrevista será llevada a cabo en una oficina privada en la clínica de GAMMA y en un día y hora a tu conveniencia. No habrá ningún pago de tu parte por participar en este estudio y no se te pagará por participar. No hay riesgos físicos en este estudio para ti con excepción de que te puedas sentir incomodo cuando estés hablando sobre tus experiencias. Si esto ocurre puedes dejar de participar en este estudio inmediatamente y la IP te recomendará hacer una cita con tu proveedor de cuidado en la clínica donde recibes tratamiento para el VIH/SIDA. Los resultados de este estudio se utilizarán para mejorar el cuidado de personas de tu edad que también tienen VIH/SIDA. Tu participación es voluntaria y puedes cambiar de parecer en cualquier momento sin temor de represalias y no tendrá ningún efecto en el cuidado que recibes en la clínica.

¿Tienes alguna pregunta? ¿Estás de acuerdo en participar en este estudio?

☐ Estoy dando el permiso para que graben mi entrevista durante este estudio.

☐ No estoy dando el permiso para que graben mi entrevista durante este estudio.

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**Nombre del Joven Participante**

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**Firma del Joven Participante**  **Fecha**

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**Firma de la Investigadora Principal**  **Fecha**

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Versión: 3 de diciembre de 2008.  Página 1 de 1  Iniciales del Padre/Madre/Tutor Legal
APPENDIX I: PARENT/LEGAL GUARDIAN PERMISSION FORM APPROVED BY

UNIVERSITY OF ARIZONA IRB
PARENT/LEGAL GUARDIAN PERMISSION FORM

Project Title: Medication Adherence in HIV Positive Adolescents living in Puerto Rico: A Qualitative Study

You are being asked to read the following material to ensure that you are informed of the nature of this research study and of how your son or daughter will participate in it, if you permit him/her to do so. Signing this form will indicate that you have been so informed and that you give your permission. Federal regulations require written informed consent prior to participation in this research study so that you can know the nature and risks of your child’s participation and can allow him/her to participate or not participate in a free and informed manner.

PURPOSE
Your child is being invited to participate voluntarily in the above-titled research project. The purpose of this project is to learn more about the experience of youth who are HIV positive, especially with taking medications for HIV/AIDS.

SELECTION CRITERIA
The Principal Investigator, Janet Rodriguez, will discuss the requirements for participation in this study with you. To be eligible to participate, your child must
1) between 15 or 17 years of age
2) are HIV positive or have AIDS
3) can speak Spanish or English
4) are able to participate in an interview for 45-60 minutes.
5) Are receiving care for HIV/AIDS at GAMMA clinic

A total of approximately 20 HIV positive adolescents will be enrolled in this study locally, some ages 18-19, and others like your son/daughter who are younger.

PROCEDURE(S)
If you give consent, the PI will contact your son/daughter by phone or email (whichever you recommend) to explain about the study. If your son/daughter is still interested, the PI will arrange to meet him/her at the next clinic appointment to explain more and to obtain his/her signature, too. The PI (Mrs. Rodriguez) will make an appointment with your son/daughter for a private interview at an office at GAMMA clinic. S/he will be asked some general questions about his/her circumstances such as age and who s/he lives with. Your child will be asked to choose a fake name to use during the interview. The interview will be conducted in either English or Spanish (whichever s/he prefers), and it will be audiotaped if you give permission.

Version Date: December 3, 2008.

Guardian Initials _____
RISKS
The things that your child will be doing have minimal risk. If s/he feels upset talking about his/her experiences and sharing sensitive information, s/he can stop participating immediately, and The PI will recommend that s/he seek care from the clinic staff where s/he is being treated for HIV/AIDS.

BENEFITS
Neither you nor your child will receive any direct benefit from taking part in this study. However, you and your child may feel some satisfaction from knowing that the information your child shares may be useful in improving care of other youth with HIV/AIDS in the future.

CONFIDENTIALITY
The only persons who will know that you participated in this study will be the Principal Investigator. The data collected from this study, including the audiotapes and transcriptions will be confidential. You will not be identified by your real name in any reports or publications resulting from the study. Representatives of regulatory agencies (including The University of Arizona Human Subjects Protection Program) may access your records, without your name on them.

PARTICIPATION COSTS AND SUBJECT COMPENSATION
There is no cost to you or your child for participating except for the time. Neither you nor your child will be paid for your child's participation.

CONTACTS
You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator, Janet Rodriguez, MSN, FNP and Doctoral Student at (787) 758-5655. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can't reach the Principal Investigator, or want to talk to someone other than the research team, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web, please visit the following website http://www.irb.arizona.edu/contact/.

AUTHORIZATION
Before giving my consent by signing this form, the methods, inconveniences, risks, and benefits have been explained to me and my questions have been answered. I may ask questions at any time and I am free to withdraw my child from the project at any time without causing bad feelings or affecting his/her medical care. My child's participation in this project may be ended by the investigator. New information developed during the course of this study which may affect either my willingness or that of my child to continue in this research project will be given to me as it becomes available. This consent form will be filed in an area designated by the Human Subjects Protection Program with access restricted by the principal investigator, Janet Rodriguez, MSN, FNP or authorized representative of the Nursing Department. I do not give up any of my or my child's legal

Version Date: December 3, 2008.
rights by signing this form. A copy of this signed consent form will be given to me.

_____ I am giving the permission to audio tape the interview.

_____ I am not giving the permission to audio tape the interview.

Subject's Name (printed)

Parent/Legal Guardian’s Signature  Date

INVESTIGATOR'S AFFIDAVIT:
I have carefully explained to the parent/legal guardian of the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who signed this consent form was informed of the nature, demands, benefits, and risks involved in his/her child's participation.

Signature of Presenter  Date

Signature of Investigator  Date

Version Date: December 3, 2008.
Guardian Initials
APPENDIX J: FORMATO DE PERMISO PARA PADRE/MADRE/TUTOR LEGAL

APPROVED BY UNIVERSITY OF ARIZONA IRB
Formato de Permiso para Padre/Madre/Tutor Legal

Título del Proyecto: Adherencia a Medicamentos en Adolescentes VIH Positivos que Viven en Puerto Rico: Un Estudio Cualitativo

Se le ha pedido a usted que lea la siguiente información para asegurarse que está informado de la naturaleza de este estudio de investigación y como su hijo/a puede participar en el si usted da el permiso para ello. Firmando este formato indicará que usted ha sido informado y que da el permiso para la participación. Las regulaciones federales requieren un consentimiento informado escrito antes de la participación en este estudio de investigación, para que usted tenga el conocimiento de la naturaleza y los riesgos de la participación de su hijo/a y pueda permitir o no que él/ella participe de una forma libre e informada.

PROPÓSITO

Su hijo/a ha sido invitado/a a participar voluntariamente en el proyecto de investigación arriba mencionado. El propósito de este proyecto es para aprender sobre el proceso de cómo se adhiere a los medicamentos un/a joven que es VIH positivo y está tomando medicamentos para su VIH/SIDA.

CRITERIOS DE SELECCIÓN

La Investigadora Principal (IP), Janet Rodríguez, discutirá los requisitos para participar en este estudio con usted. Para ser elegible a participar su hijo/a deberá:

1) estar entre la edad de 15 y 17 años
2) ser VIH positivo o tener SIDA
3) poder hablar español o inglés
4) estar capacitado para participar en una entrevista que será grabada y durará entre 45 a 60 minutos
5) estar recibiendo cuidados para el VIH/SIDA en la Clínica de GAMMA

Un total aproximado de 20 adolescentes VIH positivo serán reclutados para este estudio. Algunos de 18 a 19 años y otros como su hijo/a que son más jóvenes.

PROCEDIMIENTO(S)

Si usted acepta a que su hijo/a participe en este estudio, la IP contactará a su hijo/a por teléfono o correo electrónico (el que usted recomiende) para explicarle sobre el estudio. Si su hijo/a todavía está interesado, la IP hará los arreglos para verlo en la próxima cita a la clínica GAMMA para explicarle más sobre el estudio y obtener el permiso y la firma. La IP hará una cita con el/la participante para una entrevista privada en una oficina en GAMMA. En la entrevista se le preguntará al participante preguntas generales como edad y con quien vive. Su hijo/a seleccionará un nombre ficticio que será utilizado en la entrevista que será grabada. La entrevista será en español o inglés (el que desee el/la participante) y será grabada si usted da el permiso.

Versión: 3 de diciembre de 2008.
RIESGOS
Las actividades que su hijo/a estará haciendo durante este estudio tienen un riesgo mínimo. Si él/ella se siente incómodo/a cuando hablen sobre sus experiencias y compartan su información sensitiva, puede parar de participar inmediatamente y la IP le recomendará que busque ayuda del personal de la clínica de GAMMA.

BENEFICIOS
Ni usted ni su hijo/a recibirán beneficios directos al participar en este estudio. Posiblemente usted y su hijo/a podrán sentir alguna satisfacción de saber que la información que su hijo/a comparta podrá ser útil para mejorar el cuidado de otros jóvenes con VIH/SIDA en el futuro.

CONFIDENCIALIDAD
La única persona que sabrá de tu participación en este estudio es la IP. Los datos coleccionados en este estudio, incluyendo las grabaciones y las transcripciones serán confidenciales. Tú no serás identificado por tu nombre real en ningún reporte o publicaciones que escriban sobre los resultados de este estudio. Representantes de las agencias reguladoras, como la Agencia Reguladora de los Derechos Humanos, puede asesar tu expediente sin tu nombre en el.

COSTOS DE PARTICIPACIÓN Y COMPENSACIÓN A LOS SUJETOS
No habrá ningún costo para usted ni para su hijo/a por participar en este estudio excepto por el tiempo de estén en el estudio.

CONTACTOS
Puedes obtener información adicional sobre la investigación, tus dudas o quejas sobre la investigación llamando a la IP, Janet Rodríguez, MSN, FNP al (787) 754-5655. Si tienes preguntas con respecto a tus derechos como participante o preguntas en general o te gustaría ofrecer tu opinión sobre la investigación y no puedes conseguir a la IP o no deseas hablar con la IP, puedes llamar a la oficina del Programa de Protección de los Sujetos Humanos de la Universidad de Arizona al (520) 626-6721. (Si estas fuera del estado puedes llamar al número libre de cargos al 1-866-278-1455). Si deseas contactar el Programa de Protección de los Sujetos Humanos por vía electrónica, favor de visitar la siguiente página:
http://www.irb.arizona.edu/contact/.

AUTORIZACIÓN
Antes de dar mi consentimiento firmando este formato, los métodos, inconvenientes, riesgos y beneficios se me han explicado y mis preguntas contestadas. Puedo hacer preguntas en cualquier momento y puedo retirar a mi hijo/a de este proyecto en cualquier momento sin causar ni afectar los servicios y cuidados médicos que él/ella recibe. La participación de mi hijo/a en este estudio puede ser terminada por la investigadora principal. La nueva información que se descubra
durante el curso de este estudio que pudiera afectar mi deseo o el de mi hijo/a para continuar en el estudio se me dará a mí tan pronto se haga disponible. Este consentimiento será guardado en un área designada por la Agencia Reguladora de los Derechos Humanos con acceso restringido solamente para la IP, Janet Rodríguez, MSN, FNP o representante autorizado del Departamento de Enfermería. Yo no estoy renunciando a ninguno de mis derechos legales o los de mi hijo/a al firmar este consentimiento. Yo recibí una copia de consentimiento firmado.

____ Estoy dando el permiso para grabar la entrevista.

____ No estoy dando el permiso para grabar la entrevista.

______________________________
Nombre del Participante

______________________________
Firma del Padre/Madre/Tutor Legal  Fecha

AFIDAVIT DEL INVESTIGADOR

Yo cuidadosamente he explicado al padre/madre o tutor legal del participante la naturaleza del proyecto arriba mencionado. Yo certifico que hasta donde me alcanzan mis conocimientos, la persona que ha firmado este consentimiento fue informado/a de la naturaleza, demandas, beneficios y riesgos envueltos en la participación de su hijo/a en este estudio de investigación.

______________________________  Fecha
Firma del Testigo

______________________________
Firma del Investigador  Fecha

Versión: 3 de diciembre de 2008.  Página 3 de 3  Iniciales del Padre/Madre/Tutor Legal
APPENDIX K: DEMOGRAPHIC QUESTIONNAIRE FOR HIV POSITIVE ADOLESCENTS
IN PUERTO RICO (IN SPANISH)
Cuestionario de Demográfico para Adolescentes VIH Positivo en Puerto Rico

Favor hacer una marca de cotejo (X) al lado de las respuestas que selecciones.

Sección 1: Información General

1- Edad: ____ años

2- Pueblo de residencia y zona:
   _______________________ Zona urbana:_____ Zona rural:_____

3- Género: Masculino ____ Femenino ____

4- ¿Estás en la escuela?
   Sí ____ (Pasa a la pregunta #4) No ____ (Pasa a la pregunta #5)

5- ¿En qué grado estás?
   Elemental ____
   Intermedia ____
   Superior ____
   Vocacional ____

6- ¿Terminaste la escuela superior?
   Sí ____ No ____ (Pasa a la pregunta #7)

7- ¿Dónde estás estudiando actualmente?
   Universidad, año ____
   Instituto técnico, año ____
   Otro __________
   No estoy estudiando actualmente ____

8- ¿Trabajas?
   Sí ____ (Pasa a la pregunta #8) No ____ (Pasa a la pregunta #10)

9- ¿Dónde trabajas?
   ________________________________

10- ¿Con quien vives? **Marca todas las que aplican.**
   Ambos padres ____ Padre ____
   Madre ____ Abuela ____
   Abuelo ____ Padres Adoptivos ____
   Amigos/as ____ Novio/a ____
   Solo/a ____ Esposo o Esposa ____
11.-¿Dónde vives?
   Casa ____
   Institución ____
   Deambulante ____
   Otro, especifique ________________________________

12.-¿En qué año supiste que eras VIH positivo?
   ______________________________

13.-¿Te han dicho que tienes SIDA?
   Sí ____
   Si la respuesta es Sí, especifica el año ____
   No ____

14.-¿Estás tomando medicamentos para el VIH/SIDA?
   Sí ____  No ____

15.-¿Qué tiempo llevas tomando medicamentos para el VIH/SIDA?
   Menos de seis meses ____  De 6-10 años____
   Seis meses a un año ____  De 11-15 años ____
   De 1-5 años ____  Más de 15 años ____
APPENDIX L: INTERVIEW GUIDE OF POSSIBLE QUESTIONS TO ASK

(Spanish Version)
Preguntas Guías

Las siguientes preguntas intentan servir como guía en la entrevista que la Investigadora Principal realizara a los adolescentes, VIH positivo, participantes de esta investigación. No se pretende realizar todas estas preguntas.

1- Cuéntame cuando supiste que tenías VIH.
   Preguntas de seguimiento:
   ¿Cuales fueron tus sentimientos cuando primero encontraste que tenías VIH?
   ¿Qué pensamientos y sentimientos pasaron por tu mente?
   ¿Con quien hablaste de tu enfermedad?
   ¿Qué sentimientos o como te sientes ahora que tienes VIH?
   ¿En que otro momento te has sentido así?

2- ¿Qué haces en tu día a día para manejar o cuidarte de tu enfermedad?
   Preguntas de seguimiento:
   ¿Qué actividades haces para manejar tu enfermedad?
   ¿Qué actividades llevas a cabo para poder tomarte los medicamentos para el VIH?

3- ¿Cómo ha cambiado tu vida desde que supiste que tenías VIH?

4- ¿Qué te dijeron tus amigos cuando supieron que tenías VIH?

5- ¿Cómo aprendiste a cuidarte a ti mismo y de tu enfermedad?

6- ¿Qué cosas o eventos contribuyen a que sigas el tratamiento?

7- ¿Qué cosas o eventos contribuyen a que no sigas el tratamiento?

8- ¿Cuál ha sido para ti la parte más fácil o difícil teniendo VIH?
   Preguntas de seguimiento:
   ¿Qué ha sido para ti más fácil desde que tienes VIH?
   ¿Qué ha sido para ti más difícil desde que tienes VIH?

9- ¿Cuál ha sido para ti la parte más fácil o difícil de tomarte los medicamentos del VIH?
   Preguntas de seguimiento:
   ¿Qué ha sido para ti lo más fácil para tomarte los medicamentos del VIH?
   ¿Qué ha sido para ti lo más difícil para tomarte los medicamentos del VIH?
10- ¿A qué grado tú crees que puedes controlar o manejar tu enfermedad?
   Preguntas de seguimiento:
   ¿Hasta donde tú crees que puedes controlar o manejar tu enfermedad?
   ¿Cómo tu sabes si tu VIH esta controlada o manejada adecuadamente?
   ¿Qué tú haces para controlar o manejar tu VIH?

11- Cuéntame de una situación en particular que te hizo sentir que tu puedes cuidarte a ti mismo aun cuando tienes VIH.

12- ¿Qué mas te gustaría decir sobre como se vive, a tu edad, con VIH?

13- ¿Qué tú le dirías a un adolescente que le han diagnosticado ahora que tiene el virus del VIH?

14- ¿Qué tú le dirías para que le ayudes a manejar su enfermedad?

15- ¿Qué tú le dirías para que se pueda cuidarse solo?
APPENDIX M: INTERVIEW GUIDE POSSIBLE QUESTIONS TO ASK

(ENGLISH VERSION)
Interview Guide: Possible Questions to Ask

These questions are intended to serve as a interview guide for this research. It is not intended to do all these questions to the participants.

1. Tell me about when you found out that you have HIV.
   
   Subquestions:
   
   What were your feelings when you first found that you have HIV?
   
   What thoughts and feelings went through your mind?
   
   Who did you talked about your disease?
   
   What feelings do you have now about having HIV?
   
   What other time did you feel like this?

2. What do you do on a daily basis to manage or take care of your disease?
   
   Subquestions:
   
   What activities you do in order to manage your disease?
   
   What activities you do in order to take your HIV medications?

3. How does your life changed since you knew that you have HIV?

4. What did your friends say about you having HIV?

5. How did you learn to take care of yourself and your disease?

6. What types of things cause or contribute to you following your treatment?

7. What types of things cause or contribute to you not following your treatment?

8. What has been the easiest or the most difficult part for you in having HIV?

9. What has been the easiest or the most difficult part for you in taking your HIV medications?
10. To what degree do you believe you can control or managed your disease?

   Subquestions:
   
   To what extent do you believe your disease can be control or well managed?
   
   How do you know if your HIV is control or well managed?

11. Tell me about a specific situation that made you feel that you could take care of yourself and your HIV?

12. What else would you like to say about living with HIV at your age?

13. What would you tell a newly diagnosed HIV adolescent to help them manage their treatment and what they have to do to take care of them?
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