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HIV Medication Adherence and Psychosocial Factors in Adolescents

Clara Acosta-Glynn

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HIV Medication Adherence and Psychosocial Factors in Adolescents

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MSW – University of Connecticut, 1982

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HIV Medication Adherence and Psychosocial Factors In Adolescents

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Mural Done by the Positive Youth at the HIV Program

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Chapter 1: Introduction

This thesis focuses on the analysis of factors that influence medication adherence in HIV infected adolescents treated at the University of Connecticut Health Center and the Connecticut Children’s Medical Center (UCHC/CCMC) HIV Pediatric and Youth Program.

The effects of HIV/AIDS on adolescents and young adults are a major concern in the United States. Increasing numbers of young people are becoming infected as sexual behavior and drug use is initiated earlier in adolescent development. In addition to those adolescents who contract HIV/AIDS during their adolescence, there is another group of adolescents who have been seropositive all their lives through mother to child transmission and, as a result of more efficacious treatments, are now reaching the age of puberty. As a result, there is an urgent need for the health care providers to have the social, clinical and psychological skills to assist young people to adhere to complex therapeutic regimes and adopt a healthy lifestyle.

According to the Center for Diseases Control (CDC 2003) the number of AIDS cases for children under 13 years old is estimated to be 9,419 cases nationwide. Prevalence of HIV infected adolescents has been difficult to obtain because reporting of HIV with confidential name or code has only been initiated in recent years in Connecticut in 2002 (Conn. Epidemiologist 2001).
The CDC reported 38,490 cumulative cases of AIDS among people 13 to 24 years old through 2003. It is estimated that 10,041 adolescents and young adults with AIDS have died since the epidemic began and the proportion of adolescents diagnosed with AIDS has increased from 3.9 percent in 1999 to 4.7 percent in 2003. Because the average time it takes for the HIV infection to develop into AIDS is 10 years, most adults diagnosed with AIDS in their twenties were likely infected as adolescents or young adults. In 2003, an estimated 3,897 adolescents and young adults were newly diagnosed with HIV/AIDS nationwide, while an estimated 13,752 were living with HIV/AIDS. Experts in the health field estimate the number of adolescents and young adults to be much higher (Department of Health And Human Services 2003).

Large epidemiological surveys (applicants to job corps, military services and voluntary counseling and testing) indicate that seroprevalence of HIV is higher in certain populations of youth in comparison with the general population. Specifically, seroprevalence of HIV is greater among disadvantaged (African American and Latino) out-of-school youth, teens in the rural south and urban areas in the northeast, homeless and runaway adolescents and young men who are gay or bisexual (Conway et al. 1998). African American and Hispanic adolescents have been disproportionately affected by HIV/AIDS. African Americans and Hispanics from 13-19 years of age accounted for 66 percent and 21 percent, respectively, of the reported AIDS cases in 2003 (U.S. Department of Health and Human Services 2005).
Since the first treatment of HIV infected children with Zidovudine monotherapy in 1993, dramatic advances in laboratory and clinical research have been made. New tests that quantify plasma HIV RNA copy numbers have become available and permit a sensitive assessment of the disease progression and the adequacy of antiretroviral therapy. New medications that reduce the HIV viral load to levels that are undetectable have become available and have decreased the progression of the disease. Therefore, treatments now focus on the use of combination therapies that maximize the reduction of the virus.

The recommended guidelines for treating children and adolescents infected with HIV are a combination of antiretroviral therapies termed Highly Active Antiretroviral Therapy (HAART). Children and youth who receive such therapy have derived clinical and immunologically benefit and are living longer lives. However, the long-term effectiveness of antiretroviral medications is dependent upon the appropriateness of the chosen regimen, adequate dosing, strict follow-up of virologic response and strict adherence to the prescribed regimen. Sub-therapeutic doses of these medications will result in mutant viruses that are generally drug resistance. Resistance facilitates progression of the HIV infection, related complications and ultimately death. In addition, drug-resistant strains of HIV are a public health issue (Martinez et al. 2000). As HIV infected individuals engage in risk behaviors, transmission of such strains are potentially introduced into the community, making treatment more difficult.
Today's health service providers are facing issues of HIV infection from a chronic care perspective. Literature describing the generic approach to chronic disease (Stein et al. 1993) defines the following characteristics: the need for ongoing specialist medical care, slow degeneration of health, pain and discomfort, psychological and emotional impact, impairment to engage in usual expected activities and premature death. These characteristics are now shared by those with HIV, yet this disease has other unique aspects such as: stigma, secrecy, social isolation, interaction with family problems, such as drug addiction, multigenerational impact and multiple losses in the family (Lewis et al. 1994).

Adolescents with HIV face barriers to medication adherence due to the complexity of the medical regimen, adverse side effects, the developmental tasks of their age, lack of social support, double and sometimes triple diagnoses such as drug abuse, STDs, arrested development, mental diagnoses such as bipolar, depression, ADHD, not to mention the difficulty they have in accepting both the chronic and life-threatening nature of their illness. HAART is difficult to manage in terms of scheduling, appropriate doses, drug interaction and toxicities. Physiological changes in early adolescence affect the metabolism of certain medications. A better understanding is needed of the interrelations between developmental age and appropriate drug dosages. Despite the efforts of the pharmaceutical industry to minimize the amount of pills by combining two or three medications into one pill, the need remains for adolescents to take medications two or three times a day and to take medication under particular conditions (some on an empty stomach while others with food). The side effects of some medications inhibit the
antiretroviral activity of other drugs and the drugs can potentially cause birth defects in young pregnant women while others cause diarrhea, nausea, headache and body deformation (lipodistrophy). Some pills are big and difficult to swallow. Adolescents frequently have difficulty grasping the relationship between adherence to medication and prevention of disease progression. Asymptomatic adolescents have difficulty accepting the implications of a serious illness when they still feel well (example of concrete thinking). Others prefer the use of marihuana to the medication because according to them it made them feel better than the medications. A better understanding is needed of the interrelations between developmental age and appropriate drug dosages.

The challenges associated with adolescent developmental stages bring another set of issues that make the adherence to medications difficult. In early adolescence, concrete thinking makes it difficult for young adolescents to grasp the notion that medication adherence is needed in order to keep themselves healthy. They are more concerned with the pubertal changes such as physical appearance and growing sexual awareness. In the middle adolescent stage, the need for acceptance from peers plays an enormous role in their lives. They have the urgency to feel normal and to behave in a manner that is consistent with their peers. Their orientation to the present decreases their ability to plan for the future and reduces the priority of taking medications. Also, many adolescents have busy, unstructured lives that do not facilitate the necessary planning for appointments and medication compliance. Many high school students that begin their school day at seven in the morning do not have time to have breakfast or take their medications. The single parent household may be overwhelmed and cannot offer the
encouragement teenagers need to keep up with their medications. Many times the economic stresses of the household require that the adult is gone from the home holding two jobs or in some circumstances is involved with illegal drugs, which brings a whole set of other dynamics into the teenager’s life. The last stage of adolescent life is characterized by the establishment of independence and feelings of immortality. It is a very stressful time for some of them. Some adolescents look for independence by finding partners and living with them while others just rebel against their parents or caregivers and end up homeless or in detention centers.

The psychological effects of HIV infection on children and adolescents range from mild to devastating. Factors such as cognitive deficiencies, emotional, mental impairments and behavioral problems affect the way adolescents adhere to medication. Cognitive factors are even more important for adolescents with HIV who can have problems with language, memory, attention, as well as intellectual deficits (Wolters et al. 1995). Failure to recognize specific cognitive problems in adolescents who are or appear to be functioning at age level may cause caregivers or clinicians to place an inappropriate degree of responsibility on them.

There are clinical reports that suggest that HIV infected children and adolescents are at risk for anxiety, depression and behavioral problems. A study of antiretroviral adherence among HIV infected adolescents (Murphy et al. 2005) found that the strongest and most consistent finding was the relationship between depression and adherence. A survey of personnel participating in a multi-center Pediatric AIDS Clinical Trials
(PACTG) in 2001 revealed that learning, behavioral, and emotional problems are as frequent as 70-95% of children and adolescents with HIV at the PACTG sites (Siros 2201). Also, there is research to suggest that psychological problems in HIV children and adolescents are more related to environmental and demographic factors than the HIV infection (Mellins et al. 2003). Many HIV positive youth have lived difficult childhoods witnessing poverty, violence, substance abuse and sometimes they have been victims of physical, emotional and sexual abuse. Therefore, psychiatric and emotional diagnoses like depression, post-traumatic stress, and bipolar are frequent. Understanding the behavioral and psychological problems in HIV infected youth is critical to improving their mental health, which has been associated with poor adherence. It is vital that mental health needs be addressed, but to date, resources for mental health for HIV infected youth have been very limited thanks to continued cuts in funding.

Sexuality is a major issue among HIV positive adolescents. During no other developmental time does the human body undergo so many changes as in the adolescence stage. Sex hormones initiate the process of growth and sexual maturity. Adolescents struggling to find their sexual identity are experimenting sexually, thereby putting their health and their partner's health at risk. Twenty-five percent of STDs reported in the U.S. each year are among teenagers (U.S. Department of Health and Human Services) and for young women there is the added risk of pregnancy. There is concern that HIV positive young people are engaging in even riskier behavior than their HIV negative counterparts. Hein and colleagues (1995) found that adolescents who are seropositive had higher STD rates as a result of less condom use and engaged in substantially more
unprotected sex acts. As a result, they had almost double the number of sexually transmitted diseases and were significantly more likely to engage in survival sex, sex with casual partners, and to use condoms less often. Additionally, HIV positive male adolescents were more likely to be sexually abused than their HIV negative counterparts.

Establishing relationships that for other teens are normal is emotionally charged for HIV positive youth. They have the constant added burden of every time they meet someone new deciding whether or not to disclose their HIV status to friends and romantic partners. This can be a very painful process for teenagers who by their very nature fear rejection and isolation. They are too young to stand up to violence that could be directed at them. Keeping their HIV status secret is a reason for them to drop out of school. They may feel shame or guilt and have difficulty disclosing their condition to their peers or teachers. The whole attempt to keep their HIV status secret is another reason for them not to take their medication. If they are not taking medication, they do not have to explain or make up a lie. Family dynamics and the support they provide are regarded as crucial factors in the compliance of chronically ill adolescents. Noncompliance has been related to family conflicts, behavioral problems, avoidance behavior and denial (Degotarty et al. 1996). Many HIV infected children and adolescents live with parents who also are struggling with the disease or combating addictions and poverty. Many adolescents have lost their parents due to death or because the state has taken custody of the adolescents. Some live with relatives or have been adopted, while others are in juvenal-detention centers. Although family support is very much encouraged, adolescence and the transition into adulthood can be stressful for parents and caregivers.
The struggle of HIV positive adolescents to become independent is compounded by the overwhelming issues related to their disease, leading some of them to become suicidal, homeless, school dropouts or adjudicated youth.

HIV care providers are dealing not with an epidemic but a syndemic (Singer 2006) where a combination of HIV, STDs, mental health, substance use and poverty syndromes needs to be addressed. The enormous number of issues that are involved require that the helping system attend not only to the medical component but also to the intertwined factors that are affecting HIV positive adolescents at this unique stage in their lives.

Chapter 2: Background

Historical View of the AIDS Epidemic

On June 5, 2006, the U.S. passed its first quarter of a century of dealing with the AIDS pandemic. On June 5, 1981 the Center for Disease Control (CDC) reported the first five cases of pneumocystis carini pneumonia in five healthy young men in Los Angeles. These cases were recognized later as the first reported cases of acquired immunodeficiency syndrome (AIDS). Since that time the disease has claimed 22 million lives worldwide, including more than 500,000 in the United States (MMWR 2006).
Although countless efforts have been made to prevent and treat HIV by persons and organizations inside and outside the US government, an estimated 40,000 new persons are diagnosed every year in the United States and in 2006 more than one million people are living with HIV/AIDS in this country. HIV has disproportionately affected racial and ethnic minorities. From 1981 to 1995, whites were the predominant group of persons with AIDS (47%). However, over time the proportion has changed; from 2001 to 2004 non-Hispanic blacks accounted for 51% and Hispanics accounted for 29.5% (MMWR 2006).

The proportion of people living with AIDS two years after an AIDS diagnosis from 1981 to 1992 was 44%, for people diagnosed from 1993 to 1995 it was 64% and from 1996 to 2000 it was 85%. The latest increase was primarily due to the highly active antiretroviral therapy (HAART), which became the standard of care in 1996. The use of HAART has slowed the disease progression, reducing the number of HIV positive people who develop AIDS. Thanks to the use of these potent drugs many of the perinatal infected children are today adolescents living with HIV.

Pediatric AIDS cases were reported as early as 1982 (MMWR 2006) and were attributed to mother to child transmission. The estimated number of perinatally acquired AIDS cases peaked in 1991 at 1,650 cases (Linder et al. 1999). After 1999 HIV diagnoses declined to an estimated 144 to 236 cases in 2002 and 48 cases in 2004, thereby achieving a 59% decrease since 1992 (MMWR 2006). The reduction of perinatal infection is due to: 1) Routine HIV screening of pregnant women. 2) Some
states like Connecticut reinforced this policy by passing laws to test newborn babies if the mother had refused to be tested during pregnancy. 3) The use of antiretroviral medications for treatment and prophylaxis during pregnancy for infected mothers. 4) Avoidance of breastfeeding and the use of elective cesarean delivery when appropriate. The use of these interventions during pregnancy for infected mothers and in labor or delivery for women with undocumented HIV status has cut the rate of transmission to less than 2% compared with transmission rates of 25% to 30% without intervention. In the U. S., in spite of the effort to cut the transmission rates, there is still 7% of HIV infected pregnant women that remain undiagnosed at the time of delivery. Issues of mental health, substance use, and stigma are barriers for some women to get prenatal care (MMWR 2006). Nonetheless, there is a cohort of perinatally HIV infected children and youth that due to HAART are living longer. Despite their illness many of the infected adolescents behave like their healthier counterparts in the general population. They use drugs, have consensual sex and do not always use condoms, making them a potential source of HIV transmission. In addition, there are those adolescents who have become infected with HIV through both sexual activity and injection drug use, but primarily from sexual activity. However, drug use is an important factor even in sexually transmitted HIV in adolescents since they may engage in high-risk sex after using drugs or in exchange for drugs or money (Futterman et al. 1999). It is estimated that 40,000 people are diagnosed with HIV every year in the U.S. and the trend continues to be that almost half of them are under 25 years of age (NIAID HIV AIDS 2004).
Development of Medication Regimes

The replication of the HIV virus results in immune system damage and progression to AIDS. Periodic measurement of HIV RNA (viral load) levels helps to determine the risk of HIV disease progression and guides the clinicians as to when to start or change HAART medications. CD4 or T cell measurement monitors the dysfunction of the immune system. Most antiretroviral drugs are approved for pediatric use based on the efficacy data obtained in clinical trials for adults, with supporting data for pharmacokinetic and safety from additional trials in children (Mofeson et al. 2005). Current guidelines for the initiation of antiretroviral therapy in adults are also relevant for post-pubertal adolescents. Clinicians need to pay attention to the physiological changes of early and late adolescents because the metabolism of certain medications can vary considerably between 13 year olds and 18 year olds. The benefit of starting HAART in people with asymptomatic HIV disease and CD4 counts of more than 200 cells/mm$^3$ is unknown. However, the majority of clinicians would offer therapy at a CD4 T cell threshold of $<350$/mm$^3$. The Department of Human and Health Services (DHHS 1998) defined the principles of medication therapy for HIV for adults in 1998 and recommended them for post-pubertal adolescents with the unique considerations related to their age.
The following outline provides clinicians with a general guidance rather than rigid recommendations (DHHS 2005).

<table>
<thead>
<tr>
<th>Clinical category</th>
<th>CD4 Cell Count</th>
<th>Plasma HIV RNA</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS defining illness or severe symptoms (A)</td>
<td>Any value</td>
<td>Any value</td>
<td>Treat</td>
</tr>
<tr>
<td>Asymptomatic (AI)</td>
<td>CD4 T cells &lt;200/mm³</td>
<td>Any value</td>
<td>Treat</td>
</tr>
<tr>
<td>Asymptomatic (BII)</td>
<td>CD4 T cells &gt;200/mm³ but ≤ 350/mm³</td>
<td>Any value</td>
<td>Treatment should be offered with full discussion of pros &amp; cons</td>
</tr>
<tr>
<td>Asymptomatic (CII)</td>
<td>CD4 T cells &gt;350/mm³</td>
<td>≥100,000</td>
<td>Most clinicians recommend deferring treatment</td>
</tr>
<tr>
<td>Asymptomatic (DII)</td>
<td>CD4 T cells &gt;350/mm³</td>
<td>&lt;100,000</td>
<td>Defer therapy</td>
</tr>
</tbody>
</table>

The Pediatric Clinical Trials Group (PCTG) has been for many years the leading group to carry out medication, cognitive, behavior and psychosocial trials for pediatric and adolescent HIV patients. This group is sponsored by the National Institute of Allergy and Infectious Diseases and bases its research trials in several hospitals and health centers all over the country. In one of the publications (Broggly et al. 2005) PCTG revised the evolution of the HIV pediatric antiretroviral therapy. The study described the changes in treatment regimes that the pediatric HIV treatment went through in the U.S. from 1987 to 2003. Single or dual nucleoside reverse transcriptase inhibitors (NRTI) were used most frequently through 1997. In 1998, two years after protease inhibitors were approved for
adults, regimes of HAART that included a protease inhibitor became more frequently used for children. From 1998 to 2003, 22% of the children in the study initiated HAART with a regimen that at the time had not been recommended by pediatric guidelines. The study also demonstrated that there was a lag between the identification of HAART and its adoption in the pediatric community.

Benefits of HAART

The benefits of HAART have been demonstrated in several studies done in children as well as in adults. Murphy et al. (2001) in a research project named Reaching for Excellence in Adolescent Care and Health (REACH) found a strong association between medication adherence and reduced viral loads and also, that a CD4 level of more than or equal to 500 cells/mm$^3$ was associated with adherence. Murphy’s group investigated adherence to HAART among HIV infected adolescents recruited from 13 US cities in the project. This was the first large-scale disease progression study of HIV-positive adolescents infected through sexual behavior or injection drug use. Of 161 subjects: 7% could not correctly identify all their prescribed medications; 11% could identify them but reported never taking at least one medication; the majority (83%) reported taking all of their medications at least some of the time, but only 50% of these subjects reported full adherence. Therefore, only 41% of the sample reported full adherence. Higher levels of depression were significantly associated with decreased adherence, and a trend was found for an association between the number of medications prescribed and adherence. Researchers recommended strict adherence to HAART to
sustain suppression of viral replication, and to allow the immune system to recuperate and reduce the risk of medication resistance.

The benefits of HAART have also been demonstrated in children. Gibb et al. (2003) at the Pediatric European Network for Treatment of AIDS (PENTA) showed that taking prescribed medication was associated with a virologic response. More children reporting full adherence achieved HIV RNA of more than 400 copies/ml at 48 weeks, 79% vs. 50% reporting only some non-adherence. Comments on difficulties taking the medication were related to disclosure of their HIV status and unpleasant characteristics (flavor and pill size) of the medication. This study also acknowledged that factors relating to the caregiver, the child and the medication are all considered to be important for good adherence. Social factors such as family dynamics were important in explaining non-adherence.

**Associated Problems with Adherence**

The HIV positive adolescents face many unique challenges over and above the disease itself due to their developmental status, neuropsychological deficiencies, mental health problems and family dynamics and environmental predicaments. All of the above affect the way the adolescents adhere to their medications.

At The HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute, Mellins et al. (2004) examined child psychosocial and
caregiver/family factors influencing adherence to HAART in perinatally human immunodeficiency virus (HIV)-infected children. Although this study was done in children, many of the factors studied pertain to adolescents. Seventy-five children (ages 3-13 years) who were taking the prescribed HAART and their primary caregivers were recruited from 2 urban pediatric HIV programs. A battery of psychological assessments and self-report adherence data were collected from all caregivers and 48 children who were 7 years old or older. Forty percent of the caregivers and 56% of the children reported missed doses of medication in the past month. Families in which the caregiver or child reported missed doses (non-adherent) were compared with families who reported no missed doses (adherent). Non-adherence was significantly more associated with older children, worse parent-child communication, higher caregiver stress, lower caregiver quality of life and worse caregiver cognitive functioning. There was borderline significance when association with (1) increased child responsibility for medications, (2) HIV disclosure to the child and (3) child stress. Controlling for age, caregiver/family factors were the most strongly associated with non-adherence, including worse parent-child communication, higher caregiver stress, less disclosure to others and quality of life.

A number of studies have analyzed the impact of the HIV virus on the cognitive, neurological and behavioral functioning of people with HIV. Shanbhag et al. (2005) in a retrospective study analyzed the course of neurocognitive functioning in children before and after HAART. One hundred forty-six perinatally HIV-infected children born between June 1990 and May 2003 with at least 1 neurocognitive evaluation were evaluated for neurocognitive standard testing scores as well as diagnoses of progressive
encephalopathy, probable progressive encephalopathy, or static encephalopathy. They also assessed the impact of combination antiretroviral therapy on neurocognitive outcomes in perinatally HIV-infected patients. Researchers found that combination antiretroviral therapy is associated with improved neurocognitive outcomes in children with perinatally acquired HIV. Since 1996, fewer children have been diagnosed with progressive encephalopathy, and neurocognitive functioning is preserved over time in those deemed neurocognitive healthy. Neurocognitive testing is considered critical in detecting subtle cognitive deficits and monitoring the neurocognitive progress of HIV infected children and youth. Researchers in this study concluded that viral load and CD4 counts are marginally predictive of future neurocognitive changes in HIV persons.

Sometimes young people with problems with adherence have shown symptoms in cognitive and behavioral areas. Jeremy et al. (2005) at the Pediatric AIDS Clinical Trials Group studied the neuropsychological functioning and its correlation with viral load for previously treated HIV-infected children who underwent a change in treatment regimen. Thirteen age-appropriate measures of cognitive, neurological, and behavioral functioning were administered to 489 HIV-infected children who were aged 4 months to 17 years and had been treated previously for at least 16 weeks with antiretroviral therapy. These clinically and immunologically stable children were randomized into 1 of 7 drug treatment combinations and evaluated prospectively for 48 weeks with respect to changes in neuropsychological performance and viral load. Neuropsychological functioning was significantly poorer at baseline for the HIV-infected children as compared with established norms for their age. After 48 weeks of treatment, cognitive short-term
memory, vocabulary and fine-motor score means were still below the norm for children their age. Children with higher viral load had poorer cognitive, both-hands fine-motor, and neurological signs at baseline but single-hand fine-motor skills and behavioral functioning was not correlated with viral load. Poor neuropsychological functioning was seen for HIV-infected children and was worse for children with higher viral loads.

Descriptive studies and clinical reports have suggested that HIV-positive children and youth are at risk for behavioral problems. Inadequate control groups and sample sizes have limited the ability of investigators to consider multiple influences that place HIV-positive children and youth at risk for poor behavioral outcomes. Mellins et al. (2003) examined the unique and combined influences of HIV, prenatal drug exposure, and environmental factors on behavior in children who were perinatally exposed to HIV. Participants included 307 children who were born to HIV-positive mothers (96 HIV infected and 211 seroreverters) and enrolled in a natural history, longitudinal study of women to infant HIV transmission. Caregivers completed parent behavioral rating scales beginning when the children were 3 years old. Data were also collected on prenatal drug exposure, child age, gender, ethnicity and caregiver relationship to child and birth complications. Comparing the HIV-infected children with perinatally exposed but uninfected children from similar backgrounds failed to find an association between either HIV status or prenatal drug exposure and poor behavioral outcomes. The strongest correlates of increased behavioral symptoms were demographic characteristics. This study suggests that although a high prevalence of behavioral problems does exist among HIV-infected children, neither HIV infection nor prenatal drug exposure is the underlying
cause. Rather, other biological and environmental factors are likely contributors toward poor behavioral outcomes. Often behavioral problems encountered in HIV children and youth make adherence to medication more difficult to manage.

Clinically and immunologically stable HIV-infected children have more frequent behavioral problems than children their age. Nozyce et al. (2006) researched the behavioral and cognitive characteristics of clinically and immunologically stable antiretroviral-experienced HIV-infected children. Two hundred seventy-four previously treated HIV-infected children aged 2 to 17 years were assessed for behavioral, developmental, and cognitive functioning. Correlations between neuropsychological measures, age, and CD4 counts were investigated. The most common behavioral problems, as measured by the Conners' Parent Rating Scale, were psychosomatic (28%), learning (25%), hyperactivity (20%), impulsive-hyperactive (19%), conduct (16%), and anxiety (8%) for HIV positive children than established population norms; the mean verbal IQ was 85, the mean performance IQ was 90, and the mean full-scale score was 86. Hyperactivity was more frequent in children with a Wechsler Intelligence Scale for Children-III performance IQ of <90. Anxiety problems were more likely in children 9 years of age or older. Children with CD4 counts of less than 660 cells per mm$^3$ were more likely to be identified as having a conduct disorder.

Clinical reports from the United States indicate substantive mental health problems in perinatally HIV-infected youth that pose substantial barriers to adherence and, therefore, to optimizing their health. The study conducted by Mellins et al. (2006)
found that standardized assessments of mental health identified very high rates of psychiatric disorders, primarily in the anxiety and behavioral domains in a sample of youth with perinatal HIV infection. This pilot study explored rates and types of psychiatric and substance use disorders, as well as, emotional and behavioral functioning in perinatally HIV-infected children and adolescents. Forty-seven perinatally-infected youths (9-16 years of age) and their primary caregivers recruited from a pediatric HIV clinic were interviewed using standardized assessments of youth psychiatric disorders and emotional and behavioral functioning, as well as measures of health and caregiver’s mental health. According to either the caregiver or child’s report, 55% of youths met criteria for a psychiatric disorder. The most prevalent diagnoses were anxiety disorders (40%), attention deficit hyperactivity disorders (21%), conduct disorders (13%), and oppositional defiant disorders (11%). However, the majority of caregivers and children scored in the normative range on the symptom questionnaires on emotional and behavioral functioning. None of the demographic or child health variables or measures of caregiver’s mental health was significantly associated with the presence of a child psychiatric disorder. There was an association between caregiver’s mental health and the child’s emotional and behavioral conduct. The authors recommended that mental health interventions be integrated into medical care to help members of this vulnerable population to optimize their health and well being.
Psychiatric Hospitalizations Among Children and Youths with HIV/AIDS

Children with HIV/AIDS are at an increased risk for psychiatric hospitalizations during childhood and early adolescence compared with the general pediatric population (Gaughan et al. 2004). The Pediatric AIDS Clinical Trials Group examined long-term outcomes among HIV-infected children and HIV-uninfected infants born to HIV-infected women. Children with HIV infection were examined quarterly and laboratory data collected. Hospitalizations and diagnoses for all participants between September 2000 and December 2002 were reviewed. Among 1808 HIV-infected participants who were less than 15 years of age at the last visit date, 25 children had been hospitalized for psychiatric manifestations, 8 before enrollment in the study, 17 after entry into the study, which represent an incidence of 6.17 cases per 1000 person-years. This was significantly higher than the incidence of 1.70 cases per 1000 person-years in the general pediatric population less than 15 years of age, as reported in the 2000 National Hospital Discharge Survey, yielding a relative rate of 3.62. A total of 32 HIV-infected children, regardless of age, were hospitalized because of psychiatric illnesses. The majority of patients were admitted because of depression (n = 16) or behavioral disorders (n = 8). Fifteen (47%) underwent multiple psychiatric hospitalizations. The median age at the first psychiatric hospitalization was 11 years (range: 4-17 years); all patients had been perinatally infected. Knowledge of HIV positive status and having experienced a significant life event were both significantly associated with an increased risk of psychiatric hospitalization. No psychiatric hospitalizations were observed among the 1021 non-HIV infected members of the cohort.
Other Barriers to Adherence

Many studies have proven the efficacy of HAART slowing the progression of HIV to AIDS and prolonging the life of people that live with the virus. However, almost perfect adherence to medication regimes is needed to maintain optimum results. HAART can achieve undetectable plasma levels of the HIV virus, but if taken sporadically, the virus can become resistance to the drugs, making them permanently ineffective (Futterman et al. 1999). However, the realities of achieving adherence to medication in adolescents given their developmental stages, cognitive and behavioral issues challenge the likelihood of successful adherence to HAART. Medical and ancillary services need to pay attention to many possible problems that can be associated with the lack of adherence.

The interruption of medication and its effects on the progression of the disease are constant concerns of clinicians. There are not many studies on the matter but the one done at the Milano University in Italy (d'arminio M. et al. 2005) gives food for thought on the matter. Although this study was done on adults' interruption of medication, it is an issue that has relevance in adolescent adherence. They investigated the frequency of a first therapy interruption (TI) at 12 weeks or more after first starting the medication. Researchers wanted to identify the factors associated with TI and with therapy resumption, and to compare the risk of developing clinical events during TI and during continuous therapy. Three thousand one hundred forty two patients who started a first HAART regimen participated in the study. The main reasons for TI were patient’s
decisions (47.4%) and toxicity (24.0%). Women, injection drug users, and patients with a higher current CD4 cell count were more likely to interrupt. The median time to therapy resumption was 12 months. The higher the current CD4 count, the slower was the rate of resuming therapy; conversely, patients who stopped because of medication failure and those with a pre-HAART viral load more than 100,000 copies/mL resumed therapy sooner. Two hundred eighty-one patients experienced clinical progression at a rate of 2.6 per 100 person-years (pys) while patients who were on therapy had a 3.5 per 100 pys during TI. This study concluded that TI occurring in clinical practice is associated with an increased risk of clinical progression; hence, therapy interruption should be discouraged if it is not suggested by the clinician.

Adipose tissue alterations (ATA), which are common among persons treated with highly active antiretroviral therapy (HAART), can have substantial psychological repercussions, with a subsequent negative impact on the person’s quality of life and on HAART adherence. This factor has a devastating impact when occurring in adolescent patients who are in the developmental stage in which image is an important issue in their lives. Ammassari et al. (2002) evaluated the longitudinal relationship between ATA and adherence to HAART. Even though these studies were for adults and the cross-sectional nature of the studies preclude establishing the direction and causality of the relationship, they give a perspective on one of the problems that could affect adherence in adolescents. The analysis included all participants in the AdICoNA and the LipolCoNA substudies of the Italian Cohort Naive Antiretrovirals (ICoNA). Adherence was assessed using a 16-item self-administered questionnaire that also included a question on self-perceived fat
accumulation experienced during the past 4 weeks. ATA was diagnosed by physicians at enrollment and evaluated every 6 months thereafter. There were 207 patients with a median age of 35 years; 73% were men; 34% acquired HIV through injection drug use. At baseline, non-adherence was reported by 63% of the participants, and ATA was self-perceived by 15% and clinically diagnosed in 25% of the cases. Patients with good adherence at baseline were more likely to develop ATA and developed it sooner. Self-perceived ATA at baseline was independently related to subsequent non-adherence, but clinically diagnosed ATA was not related to non-adherence. Patients' adherence to HAART is a dynamic process that interacts with ATA. Better adherence was associated with a higher risk of subsequent occurrence of ATA while patient-perceived onset of morphologic alterations can reduce adherence to antiretroviral therapy.

Depression symptoms and disorders in adolescents are often under identified and under treated (Reynolds, 1994). Many studies have found an association between depression and the lack of adherence to medications. If the severity or the duration of depression episodes could be decreased maybe adherence can be improved. Murphy et al. (2005) at the Health Risk Reduction Projects, Department of Psychiatry, University of California, followed a cohort of adolescents with HIV to investigate long-term antiretroviral therapy adherence and factors associated with adherence. The strongest and most consistent finding in this study was the relationship between depression and non-adherence. Two hundred and thirty one adolescents infected with HIV with mean age of 18.4 years; 72.7% female; 74.9% African American from 13 cities throughout the United States were assessed at 3-month intervals. At the initial visit, approximately 69% of the
adolescents reported adhering to the medications. Adolescents in the late stage of the disease were found less likely to be adherent compared with those in the earlier disease stage. Less alcohol use and being in school were associated with adherence. Also, longitudinal adherence was investigated among 65 subjects initially adherent with available information for at least 4 consecutive visits. The median time to non-adherence was 12 months and failure to maintain adherence was significantly associated with the younger age and depression. Among adolescents who attained an undetectable viral load, only about 50% maintained an undetectable viral load for the year. The researchers advise that new treatments for adolescent depression may assist in improving adherence for a majority of adolescents with HIV.

As illustrated above, there are many factors that could impede positive adherence to HIV medications for adolescents. Trocme et al. (2002) in France examined the question: Is poor treatment adherence, frequently observed in the HIV positive adolescent population, due to the adolescent’s developmental process, their experiences while living with HIV, or their lack of information about the disease or treatment? Researchers interviewed 29 HIV positive adolescents in one pediatric reference center. Confidential interviews were performed according to a standard questionnaire. They found that 70% had stopped taking their medications at least once since starting treatment. Adolescents stated that treatment was the major barrier to their sense of freedom. One-third of them decided to stop it for more than one month. Seventy percent had good information about their sickness and the potential consequences. Fifty-five percent expressed feelings of loneliness or depression, yet 75% considered they had a pleasant life because they had a
normal life. Researchers attributed this fact to the secrecy and silence about their HIV condition. The authors concluded that being dependent upon a treatment is a major constraint in the lives of HIV positive adolescents. Although adolescents were fully informed, the deliberate interruption of treatment could attest to their expressed need for autonomy.

Also, in a factor analysis of the barriers to adherence to HAART therapy among HIV-infected adolescents done through the REACH project (Murphy et al. 2003), it showed that there are two factors accounting for the largest proportion variance in adherence: (1) medication-related adverse effects (both physical and psychological) and (2) complications in day-to-day routine and the adolescent’s life style, busy schedules, medication interference with their activities, lack of support from a dysfunctional family, homelessness. In this study, adherence was tied closely with daily routines and supports the assumption that working closely with adolescents to improve their organizational skills is necessary to improve adherence and provider-level intervention is needed.

Approaches to Enhance Adolescent Adherence to Medications

Several approaches have been used among the community of providers with the goal of providing better health care and motivating youth to maintain adherence to their medications. As Simone et al. (2003) stated, “Adherence has been proven to be the Achilles’ heel”. Simone’s group analyzed the antiretroviral therapy adherence intervention studies published through January 2003. In the 21 studies published up to
2003, four interventions were identified, although all of them were for adults that could very well be used with adolescents: cognitive-behavioral, behavioral, directly observed therapy and affective therapy. Another four randomized controlled trials suggested promising effects: pharmacist-led individualized intervention, cognitive-behavioral, educational interventions based on self efficacy theory, and cue dose training when combined with monetary incentives. Another 39 federally funded studies offer better methodological sophistication and include new strategies, such as the use of handheld devices, two-way pagers and alarm medication vials. To our knowledge there are no publications on the effectiveness of these devices, or their long-term efficacy.

Providers serving adolescents who aimed to improve adherence and therefore the health and survival of HIV infected people, have developed some models that can be helpful. A family group approach to increasing adherence to therapy in HIV-infected youth was studied at the Division of Adolescent and Young Adult Medicine/Burgess Clinic Children's National Medical Center (CNMC) in Washington, DC. Lyon et al. (2003) describes the development of a novel, pilot program in which a combined family group and peer approach was used to increase adherence to antiretroviral therapy in HIV-infected youths. Twenty-three HIV-positive youths, 15-22 years of age and 23 family members or "treatment buddies" participated in one of three 12-week programs. The intervention had six biweekly family/youth education sessions and six biweekly youth-only education sessions. Devices to increase adherence to antiretroviral therapy such as pillboxes, calendars, and watch alarms were introduced at youth-only sessions. Eighteen of the 23 youths completed a group. Ninety-one percent of the youths self-reported
increased adherence to medications after completion of a group. Four participants experienced reduction in viral loads to undetectable levels during the intervention. Two participants continued to decline antiretroviral medications at the end of the intervention and demonstrated no decrease in viral load. Participants tested five devices and rated the multiple alarm watch as the best aid for improving adherence to medication. Family/treatment buddies rated the overall program as highly helpful, citing social support as most valuable. An unanticipated benefit was an increase in other health behaviors, including medical and dental appointments, hepatitis B and influenza immunizations, and referrals to mental health and substance abuse treatment.

The need to integrate mental health and primary care service delivery for adolescents living with HIV/AIDS has been documented in the description of NOAH (No One Alone with HIV) program. Accessibility, flexibility, and cultural specificity are qualities necessary, but generally lacking, in existing models of integrated care. Feingold et al. (1993) describes NOAH at the Boston General Hospital of Psychiatry. This is an innovative, hospital-based program of family-focused HIV mental health services. NOAH is designed to meet the needs of primary care providers, allied professionals/paraprofessionals, and the diversity of inner-city patients they serve. Central to the model are population-specific "family health facilitators," who collaborate with providers by offering mental health interventions at one or more levels along a continuum of service intensity. Whenever possible, primary care team members are empowered to manage mental health problems directly. When more intensive services are required, responsibility for direct intervention transfers to the family health facilitator.
With the locus of inner-city HIV primary care shifting from hospitals to neighborhood health centers, this hospital-based program has been extended into the community to support the early integration of mental health and primary care services at the community level.

Based on the belief that integration of services can lead to improvement in treatment adherence, and with a considerable number of HIV positive adolescents and young people presenting issues with co-occurrence of mental health and substance abuse, the need to provide integrated care is gaining prominence. Some evaluations of programs sponsored by the Ryan White Comprehensive AIDS Resource Emergency Care Act were published in AIDS CARE 2002. The descriptive evaluation data for one of the Center’s model of multidisciplinary HIV care showed that people living with HIV, who received case management, mental health, chemical dependency services, and transportation co-located with primary care were significantly more likely to receive regular HIV and primary care (Sherer et al. 2002). The model featured one-stop shopping service delivery. Available on-site services included integrated services for women, children and families, health education, HIV testing and counseling and direct links with public and social services.

Beliaeva et al. (2003) in Russia studied approaches to enhancing adherence of HIV-infected patients receiving antiretrovirus therapy. Twenty-five patients (including 3 females) aged 18 to 45 years receiving VAART (fortovasa + norvir + videx, and viramun) were examined. During treatment, group classes were conducted to enhance
patient adherence to the therapy and were followed by individual counseling in order to consolidate the obtained effect. The adherence to the therapy was rated by the patients' self-reports. There was an increase in the activity and openness of those who attended group classes and positive changes were seen in their self-assessment. Approaches to enhancing adherence and a model school for HIV-infected individuals were developed. It was shown that a combination of patients' awareness of different HIV-infection-associated problems with counseling allows treatment motivation to be increased.

A project derived from lessons learned from the Special Projects of National Significance Program, a study done in several sites, describes a model whose focus is to enroll youth with HIV into care through new or existing HIV service networks, and direct recruitment via street outreach and other similar methods. At both the national and local levels there are five major elements that capture the innovations of the collective service method: (a) peer-youth information and dissemination; (b) peer-youth advisory groups; (c) peer-youth outreach and support; (d) professional, tightly linked medical social support networks; and (e) active case management and advocacy for individual clients as well as the programs themselves, to link the various components together. One of the most important factors in the model leading to success is that youth and professionals share an equal partnership in all stages of program design, planning, and implementation. Youth and professionals each share their expertise in a dynamic process. In addition, active case management is crucial; not only to ensure that clients receive needed services, but also to ensure that the programs themselves run in a coordinated, tightly linked way. Given needs of adolescent clients and existing adult-oriented service networks, the use of
active case management and the active participation of youth in the service systems are critical.

The above background review gives a broad picture of the numerous elements that depict medication adherence in adolescents from different perspectives. There are abundant studies that encompass relevant issues from pediatric to adulthood that affect adherence in adolescents. Starting from the first pediatric cases to the current HIV positive adolescent population, the programs review issues such as: disease progression; medication benefits; family dynamics; cognitive, behavioral, mental health issues and models of practice. The following study tries to assess some of those elements at the UCHC/CCMC HIV Pediatric and Youth program.

Chapter 3: Methodology

The UCHC/CCMC Pediatric and Youth HIV Program first began providing pediatric HIV research care and family support services under the auspices of the University of Connecticut Health Center (UCHC) Pediatric HIV Program in 1989. The approach to care is child/youth centered and family focused because of children’s nearly complete dependence on their caregivers as well as the two generational (mother and child infected) aspect of pediatric HIV. The program provides HIV medical care and research as well as support services. There are two weekly clinics to monitor the HIV related issues of the infected children and youth and to test newborns of HIV infected mothers. Another weekly clinic carries out the clinical research and two bi-monthly
clinics offer families the opportunity of the parent and child being seen by their HIV specialist in only one visit. A unit of five social workers makes available an array of services such as: case management, support groups, mental health counseling, prevention education and HIV counseling and testing. The program is the primary provider of pediatric and adolescent HIV care for Hartford, Tolland and Middlesex Counties and serves over 184 clients including some of the parents and siblings of HIV positive children and youth.

As the children in the program grow into puberty and adolescence, there is the need to learn more about the issues and social needs relevant to development and specifically how this affects adherence to the HIV medications. This was a descriptive study of 30 HIV positive youth that attend the UCHC/CCMC Pediatric, Adolescent and Mother/Child Clinics. The specific aims for this study were medication adherence and the factors related to family, peer and community support, services used by the adolescent/family, cognitive, emotional and behavioral problems and the relationship between the adolescent’s knowledge of medication and health status and adherence. The dependent variable was adherence to HIV medications obtained through the measurement of HIV RNA levels and CD4 counts. Three domains were measured as independent variables: family support and community involvement with the family; adolescent development (physical, cognitive, emotional and social); and adolescent knowledge of HIV medications and their benefits and trust in medical providers.
Sample

The sample was taken from the program's 184 clients, excluding anyone not positive or not between the ages of 13 to 24 years old. The study was thus offered to HIV positive patients ages 13 to 24 attending the clinics. Thirty-six clients were recruited at the initiation of the study. Completed data were collected on 30 participants; one adolescent died, 3 moved out of the area and 2 transitioned to adult care. This study took place from January to December 2005. There were 16 female and 14 male participants. The majority of them were minorities: 56.7% Hispanic, 20% African-American, 13.3% White and 10% mixed heritage. Fourteen of the adolescents lived in Hartford, 5 in New Britain, 3 in West Hartford, 2 in East Hartford and the other 6 lived in small towns in the Northeast region of Connecticut. Approval from the CCMC Institutional Review Board was obtained. Written consent forms were signed by each of the participants.

Data Collection

An unstructured interview to define the content of the domains to be associated with the adherence was piloted with 10 patients and their families at the Yale University HIV Pediatric Program. Information from these interviews was used to develop a structured survey that was administered to the UCONN/CCMC patients who consented to participate in the study. The survey was administered to each youth privately by the trained social services team that kept in mind the adolescent’s developmental age and
appropriateness of cognitive level. When needed, the social worker explained the meaning of the question in order for the adolescent to give the most informed response.

In addition to the structured questionnaire data was collected from record review (medical and social services). Quantitative data regarding levels of CD4 and viral load counts were collected through the medical record review. Disease classification was measured according to CD4 clinical classification (MMWR 1992) for levels of suppression. Levels of suppression were based on the following categories: category 1 “no suppression” equal to ≥ 500 CD4; category 2 “moderate suppression” equal to 200 to 499 CD4 and category 3 “severe suppression” equal to or less than 200 CD4 count.

The family support domain was measured through a number of variables that define the family’s dynamics, such as: youth that have a biological parent alive, parent/caregiver’s education, household members, exposure to substance abuse and violence, and whether family/caregiver was ever incarcerated. Community support was obtained by measuring the number of community agencies the adolescent/family has used including the Department of Children and Families (DCF) involvement with the family.

Measurements for the medical domain were geared to obtain the level of adherence. Measurements were taken on: adolescents’ knowledge of medications they were taking, number of doses missed in the last two weeks, knowledge of the relationship between lab results and the medication taken, who was responsible for administering the medication (themselves or caregiver) and reasons for missing medications. Eight
parameters were given to the subject to choose in this variable: forgot, slept through, away from home, side effects, depressed, reminded me I am HIV, concern with disclosure, and don't feel sick. The developmental domain had three variables: cognitive, emotional and behavioral. To measure cognitive development, factors such as special education and appropriate school grade were included. The emotional variable was evaluated by asking the youth several questions: Were you ever abused (physically, sexually or emotionally)? Have you felt depressed in the last month? Have you thought about running away? Have you had suicidal thoughts? Have you tried to commit suicide? For the behavioral variable, factors taken into account were: problems in school, court involvement, sexual involvement and use of substances.

Chapter 4: Results

Demographics

Participants in the study included: 16 females and 14 males, the majority of them were minorities: 56.7% (18) Hispanic, 20% (5) African–American, 13.3% (4) White and 10% (3) were of mixed heritage. For many, HIV is not their main concern since issues of poverty keep them struggling to survive. Sixty percent, (18) families in the study had an income of less than $20,000 a year and their main sources of income were: 23% (7) employment, 37% (11) government and 40% (12) a combination of employment and government subsidy. As a result, families used community resources, especially the Ryan White Care Act network of agencies that provide emergency financial assistance.
such as subsides for rental housing, transportation, utility bills, medical and dental bills, food vouchers, mental health and substance abuse programs. All the families except ten percent (3) used these Ryan White services.

Levels of infection

At the time of the study, 73% of the youth were category 1 with CD4 counts over 500 cells, 16.7% were category 2 with CD4 counts 500 to 200 cells and 10% were category 3 with CD4 counts under 200. Regarding viral load, 30% were undetectable, 13.3% had counts between 200 to 1,000 copies and 43.4% had less than 20,000. Only one youth had over 100,000 copies at the time this variable was documented.

Evolution of Family Dynamics

In the beginning of the AIDS epidemic most parents died before their infected children, so the children used to live with grandparents or relatives. Today’s scene for the adolescents is different. Even though 73% (22) of youth in the study still had biological parents alive, only half of them, 11, lived with their parents and of those, only 4 lived with both parents and 7 with a single parent. Some of these families struggle to do good, especially those whose parents are recovering drug addicts and still provide stable homes. However, for others living with biological parents, their situation has not guaranteed a better life for them. Four of them have been involved with DCF, six had to deal with dysfunctional families, and four have addicted or recuperated parents. All but one has
seen their parents dealing with their own disease. Among the 63% (19) of the youth not living with biological parents, 32% (6) were adopted through DCF as children and only three of them still live with the adopting parents. Seventeen percent cent (5), all females, had established their own homes, another 10% (3) were transient, one was living in a shelter, one was living with friends and another ended up in DCF custody and has been in different foster homes. Another 16.7% (5) were in juvenile detention or mental health programs. Two of them were in mental institutions due to the traumatic experiences they experienced during childhood and three were in detention at the time of the study. Below is one story (cases in this study have been taken from social services records and names are pseudonyms):

Maria, whose mother died when she was a baby, lived with an aunt until she was thirteen. As a teenager she started to have friction with her aunt because of the limitations the aunt was imposing. Looking for a way out, she went to live with her father, who up to this time was not very involved with her. During the time she was with the father, she did not receive any support or attention from him or his girlfriend. On the contrary, while staying at the father’s house she did not take her medication, did very badly in school and lacked the basics because he was taking her social security benefits. Depressed and rebellious, she left her father’s house to live with another aunt. This arrangement did not last long because of her behavior and sexual activity. After she was asked to leave the aunt’s house, she was homeless and pregnant and living with friends. Today she is dealing alone with the issues of
her pregnancy and medication adherence in order to avoid transmission of the HIV virus to her baby.

**Mental Health**

The mental health issues in this group of adolescents are significant. They face depression, anxiety, denial and rebellion issues that may interfere with adherence. Youth in the study have experienced a lifetime of traumatic events that are manifested in symptoms such as aggression, lack of trust, lack of interest, lack of social skills, truancy, depression, runaways, suicidal thoughts and suicidal attempts. In spite of the fact that 80% (24) of the adolescents have shown emotional problems and signs of mental disorders, only 33.3% (10) have been diagnosed and even fewer have received professional help. Sixty seven percent (20) of youth in the study have witnessed violent acts in their homes or neighborhoods and 63% (19) have been involved in a fight. Sixty percent (16) of them have been exposed to the change of different foster homes or institutions, or have seen their parents frequently changing partners. For many of the children and youth, the medical providers and case managers have been the most consistent figures in their lives. These life experiences cause major problems for the youth when they deal with issues of trust. Trust in HIV infected adolescents is very much attached to the issue of confidentiality about their HIV status and is one of the reasons for them to be isolated socially.
Another parameter used to measure mental health was abuse, whether physical, emotional or sexual. Although 30% (9) did not consider themselves abused, 58% thought their caregivers emotionally abused them. Emotional abuse is a complex factor to measure appropriately. Due to the adolescents developmental stage in which they struggle for their independence, restrictions from parents or caregivers could be perceived as abuse. Although some of the youth showed signs of the possibility of being sexually abused as children, only two cases were confirmed.

Depression in young people is associated with poor academic performance, social dysfunction, substance abuse, and suicidal attempts. Depression in this group of youth comes from issues of their family life, coping with their disease or parents’ disease, problems at home or school or with their peers. Fifty-seven percent (15) of the studied youth reported being depressed. When they were asked for the reasons for their sadness, 26.7% (8) said problems in the family; 20% (6) being sick or parent being sick; 20% (6) discrimination, 16% (5) missing their biological parents; and 6.7% (2) worried about the future. Fifty percent said they shared their feelings with their parents or a member of their family when they felt sad while 33.3% (10) said they talked with no one and that they tried to “tough it up” by isolating themselves, listening to music or trying to sleep. Only 13.3% (4) shared their sadness with a friend, usually their partner. And while most reported having friends, when it came to having support because of their HIV condition, only 26% (8) said they have one or two friends that knew about and could talk to them about it. They try to internalize their feelings regarding their condition and prefer not to talk about it because it is very painful.
Another way depression was expressed was through suicidal thoughts or attempts; 23.3% (7) have had suicidal thoughts and two of these attempted suicide. The following two case studies illustrate the often dire situations that these youngsters face:

Joyce was removed from her home at the age of 9 because of alleged sexual abuse by one of the family members. She lived in different homes and because of a suicidal attempt ended up in a mental facility. This institution has been providing therapy and working with her in finding a foster home or reunification with her mother. She has not been able to work out her own feelings. It seems that her fears interfere with an ability to achieve a more stable living arrangement. On the other hand, it also appears that she wants to be in the institution because it has been the one place that has given her the most consistent support.

Charles, a 16 year old young man in detention, spent a life of desperation with his mother's erratic behavior. She used drugs, engaged in prostitution, had two HIV infected children and finally committed a dramatic suicide which he witnessed. After this traumatic event, he got in trouble with the law and was detained. When the court wanted to send him home, his grandmother rejected him and he was sent to a detention institution. He has been under DCF custody since then. Although his parole officer, DCF and hospital social workers advised him to stay with DCF in an alternative home, he looks forward
to living with his sister, who does not offer much safety since she is also HIV positive and is bipolar and cannot offer him much stability.

Disclosure of the HIV diagnosis is very difficult and in many cases can cause many emotional problems because of the stigma attached to the disease. Even though the majority of the adolescents in the study acquired the disease through their mothers, the stigma is still very much present in their lives. For these adolescents, stigma plays a role in keeping their HIV status secret, as do their fears about being treated differently at an age when they just want to be part of a group.

Joanne’s fears about disclosing her diagnosis were so intense that she dropped out of school after she told the principal and nurse about her HIV status. She had been encouraged to disclose by the program staff because she was not taking her medications and the school nurse could give them to her. After dropping out of school, she continued not taking her medications and got involved with drugs. One of the reasons why she dropped school was the fear she would lose her friends, but the school counselor and her school friends were at her bedside at the hospital when she died.

Cognitive Impairments

Cognitive level is a very important issue related to adolescent medication adherence. The HIV virus can attack cells in the brain leading to damage of the central
nervous system. Studies have tried to assess HIV impact on cognitive, neurological and behavioral functioning or neuropsychological functioning (see chapter 2). The pathology of neuropsychological deficits in children and youth with HIV is difficult to ascertain because these deficits may be associated with factors other than HIV including prenatal drug exposure, low level of parents/caregivers’ education, discordant mother/child interaction, poverty and other developmental issues.

Difficulties with short-term memory, vocabulary deficiency and comprehension of simple statements have been identified as neuropsychological symptoms. Assessing the cognitive functioning of youth in this study through neuropsychological testing was not possible because of the lack of financial resources to perform this test on each participant. Other indicators used as proxies included: involvement in special education and appropriateness of school grade and age and school dropouts. Half of the youth in the study qualified for special education. Because of the complex process for youth to be identified as a student with special needs for education, this may under report the actual need for special education. When one compares the current grade level of the youth to the age appropriate norms, 40% (12) were at normal grades or graduated from high school at normal age level, although one of them was socially promoted. Twenty-seven percent, 8, of the youth were one year behind, 10% (3) were two years behind, 3.3% (1) was more than 3 years behind. Twenty percent (6) had dropped out of school. Everyone who dropped out was female; all but one of these had become pregnant and could not maintain schoolwork and motherhood. For these young mothers, the lack of education
put them at a disadvantage in properly raising their children and obtaining jobs that could sustain them financially.

**Criminal Justice Factors**

A high rate of interaction with the judicial system was observed, especially for the males. Forty-eight percent (14) had had problems in the school such as: skipping classes, fighting, defiant behavior and carrying knives. When they are charged with any of these offenses before age 16, they go to court and sometimes end up in juvenile detention for a short time. Usually the charges are for truancy or breach of peace. If they accumulate new charges and are still under 16, they go to juvenile detention for a longer period at the Connecticut Junior Republic. Since Connecticut is one of three states that treats youth 16 years and older as adults, at this age they are treated as adults and end up in jail. More than half of the youth in the study have had problems with the justice system; 26.7% (8) had been in court and another 26.7% (8) had been detained. Forty percent (12) of the youth had smoked marijuana and one of them was using hard drugs. There are many conditions that promote unlawful behavioral problems for these youth. Seventy-three percent, 22, of the youth in the study have been exposed to substance abuse or selling drugs. Fifty percent of their family members or caregivers have been incarcerated.

The family’s financial situation is another problem that puts these youth at risk for criminal activities. Some of them have been adopted or live with relatives and some are subsidized by DCF or social security. The subsidy has presented a problem in some of
these families because when youth reach 18 and are not in school, the financial assistance
to the family is terminated. Lacking this support makes it more difficult for the families
and so some of these youth have been asked to leave their homes:

Fulano, a 18 year old who is adopted, was put out of his house as soon
as the financial assistance was cut. Since then, he has been in
temporary shelters. He was put in jail because he had stolen some
items in a store and damaged some cars. His resilience and the work
of his case manger have helped him to survive eight months of
homelessness and emotional distress.

In spite of the traumatic events they have experienced with their families, family ties are
very important:

Pablo, who lived with his grandmother, was in detention for truancy.

He stole a car from the detention to go to see his elderly grandmother
because he was concerned about her because she has cancer. His
grandmother has been his main caregiver because his mother has spent
most of her life using drugs or in jail.

**Sexual Behavior**

The sexual activity of the HIV infected youth was found to be similar to that of
the national picture. A trend seen in the study was that HIV positive youth engaged in
early sexual activity. Fifty percent (15) were sexually active at the time of the study and
12 of these were female. Four of the females were infected through sex at a very early age. Some of the adolescents have shown very aggressive sexual behavior, going on sexual experimenting rampages. For two of them, an underlining mental issue such as bipolar disorder contributed to this behavior.

In spite of the program’s constant sexuality education to prevent these adolescents from transmitting the infection, only one youth said she had always used condoms, while 14 reported using condoms only sometimes. One reported having one partner, two had over 20 and 12 had between 5 and 10 partners. For female adolescents, pregnancy further complicates the existing challenges of poverty, traumatic experiences, poor social support, adolescent development stages and mental disorders. Eight of the 12 sexually active female youth have children but only two children were HIV infected. They were born before 1996 and the establishment of the AZT protocol to prevent the maternal child transmission of HIV. Early sexual activity often results in pregnancy and they are not able to maintain schoolwork and motherhood. One of them initiated sexual activity at the age of nine, had her first baby at 12 and her second at 15. This aggravated the girl’s home situation where the mother is also HIV positive and has two young children as well as raising three grandchildren, her daughter’s two and another one from her oldest son.

The transmission of HIV to others is a serious issue. It is not only about HIV positive adolescents’ sexuality and how they perceive it; it is also a public health issue. A big factor is disclosure. If teens are able to disclose, they may be able to negotiate the use of condoms with their partners. Seven of the fifteen sexually active adolescents had
disclosed their HIV diagnosis to their partners. Eight had not told their partners about their HIV status.

**Adherence to Medication**

Adherence to medication directly affects HIV status. Adherence for this study was defined as the proportion of prescribed medications taken to the missed doses in a two-week period. For the analysis, four adolescents who were not taking medication and 5 that were in institutions were not included. For the remanding 21, the median adherence was 89%. This cohort was divided using the median into high adherence (11 youth and low adherence 10 youth). Medication adherence was examined by demographic characteristics, psychosocial factors and medical issues. Most comparisons were not statistical significant, though some trends were present. The small sample size provided limited power to explore correlations.

There were more males than females in this cohort and Hispanics were 57% of the participants. In the low adherence group, more parents/caregivers had not graduated from high school (57.1%) compared to parents/caregivers in the high adherence group (42.9%). Also, families in the low adherence group have had more involvement with DCF (58.3%) than the families with no DCF involvement (33.3%). Income was low for most of the families in both groups with few families earning more than $30,000 dollars a year.
Table 1. Percentage of Youth not in Institutions Taking Medication by Demographic Characteristics by Adherence.

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<th>Characteristics</th>
<th>N</th>
<th>High adherence</th>
<th>Low adherence</th>
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<td>Gender</td>
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<tr>
<td>Male</td>
<td>11</td>
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<td>Female</td>
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<td>50%</td>
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<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>12</td>
<td>75%</td>
<td>25%</td>
</tr>
<tr>
<td>African American</td>
<td>3</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>3</td>
<td>66%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Mix Heritage</td>
<td>3</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Parent/Caregiver education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not graduated from high school</td>
<td>7</td>
<td>42.9%</td>
<td>57.1%</td>
</tr>
<tr>
<td>Graduate from high school</td>
<td>14</td>
<td>57.1%</td>
<td>42.9%</td>
</tr>
<tr>
<td>Family DCF involvement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12</td>
<td>41.7%</td>
<td>58.3%</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>66.7%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Annual income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30,000</td>
<td>16</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>30,000 +</td>
<td>5</td>
<td>60%</td>
<td>40%</td>
</tr>
</tbody>
</table>

As the literature revealed, (Shanbhag 2005, Jeremy 2005, Nozyce 2006) of those with cognitive problems, as measured by school appropriate grade level, 72% had low adherence (Fisher exact, p=.030). A trend was found in youth witnessing violence where the high adherence group had a higher percentage with 66.7% (Fisher exact, p=.198). Although the impact of family support was not statistically significant, those adolescents who were transient or living by themselves had low adherence, with 60% of them in the low adherence group. Regarding mental health, also mentioned in the literature review (Mellins 2006, Gaughan 2004), two of the participants were hospitalized for psychiatric disorders before the recruitment. Depression was higher in the low adherence group.
(χ²=12.982, p=.024); 60% in the group self-reported depression, compared to 40% in the high adherence group. Half of the study participants in both adherence groups had emotional problems, largely determined through chart review. More sexually active youth were in the high adherence group (62.5%) than in low adherence group. More youth in the low adherence group (55.6%) had been involved with the judicial system. Substance abuse, especially marijuana, was higher in the low adherence group (66.7%) than in the high adherence group. Youth in the high adherence group also had more friends that knew about their HIV status (66.7%).
Table 2. Percentage of Youth, no in Institutions, Taking Medication by Psychosocial Factors by Adherence

<table>
<thead>
<tr>
<th>Psychosocial Factors</th>
<th>N</th>
<th>High adherence</th>
<th>Low adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems</td>
<td>11</td>
<td>27.3%</td>
<td>72.7%</td>
</tr>
<tr>
<td>No problems</td>
<td>10</td>
<td>80%</td>
<td>20%</td>
</tr>
<tr>
<td>Witness violence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12</td>
<td>66.7%</td>
<td>33.3%</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>33.3%</td>
<td>66.7%</td>
</tr>
<tr>
<td>Living arrangements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self and homeless</td>
<td>5</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>With parents/caregivers</td>
<td>16</td>
<td>56.3%</td>
<td>43.8%</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>63.6%</td>
<td>36.4%</td>
</tr>
<tr>
<td>Emotional problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Sexually active</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>62.5%</td>
<td>37.5%</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
<td>46.2%</td>
<td>53.8%</td>
</tr>
<tr>
<td>Involved with judicial system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>44.4%</td>
<td>55.6%</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>58.3%</td>
<td>41.7%</td>
</tr>
<tr>
<td>Substance abuse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>33.3%</td>
<td>66.7%</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Have friend that know about diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>66.7%</td>
<td>33.3%</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>46.7%</td>
<td>53.3%</td>
</tr>
</tbody>
</table>
Concerning the medical issues, the high adherence group was more likely to have high CD4 counts than the low adherence group ($\chi = .130$ and $P = .192$). Reasons for not taking the medication was significant ($\chi^2=12.982$, $p= .003$). All those with “family problems” were in the low adherence group, while all those that “slept through” were in the high adherence group. Being”depressed” and “forgetting” to take the medication were the same in both groups. As for viral load count, more of those with undetectable amounts were in the high adherence group (80%). There were more youth who understood the relationship between laboratory results and medication adherence in the high adherence group (62.5%). While only 50% of those not responsible for taking their medications were in the high adherence group, 81.8% were in the low adherence group (Table 3).

In general, this group of HIV+ adolescents is healthy. Only 3 youth were hospitalized during the research period, two in the high adherence group to deliver babies and one in the low adherence group for HIV related issues. In the low adherence group 3 youth went to the emergency room, one for treatment because of a car accident and two for HIV related issues. Regarding clinical visits missed, one missed one appointment and another missed two appointments in the high adherence group. In comparison, 8 youth missed clinical visits in the low adherence group, including 4 youth that missed one appointment, one that missed two appointments; two that missed three and one that missed more than four appointments.
Table 3. Percentage of Youth, not in Institutions, Taking Medication by Medical Issues by Adherence

<table>
<thead>
<tr>
<th>Medical Issue:</th>
<th>N</th>
<th>High adherence</th>
<th>Low adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 counts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;200</td>
<td>2</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>200+</td>
<td>19</td>
<td>57.9%</td>
<td>42.1%</td>
</tr>
<tr>
<td>Reason for not taking medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family problems</td>
<td>6</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Depression</td>
<td>4</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Slept through</td>
<td>3</td>
<td>100%</td>
<td>0%</td>
</tr>
<tr>
<td>Forgot</td>
<td>4</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Viral load count</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undetectable</td>
<td>5</td>
<td>80%</td>
<td>20%</td>
</tr>
<tr>
<td>1,000 – 10,000 copies</td>
<td>10</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>10,000 – 20,000</td>
<td>3</td>
<td>67%</td>
<td>33%</td>
</tr>
<tr>
<td>20,000 – 50,000</td>
<td>3</td>
<td>67%</td>
<td>33%</td>
</tr>
<tr>
<td>Understand lab/adherence relationship</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>62.5%</td>
<td>37.5.3%</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
<td>46.2.2%</td>
<td>43.7</td>
</tr>
<tr>
<td>Responsible for taking medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11</td>
<td>81.8%</td>
<td>18.2%</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>50%</td>
<td>50%</td>
</tr>
</tbody>
</table>

In summary, the factors associated with high and low adherence in this sample of 21 youth were consistent with the issues demonstrated in the literature review. Youth not adherent to medication have problems in the areas of cognition and mental health and have less family and peer support. Youth in the high adherence group had better CD4 and viral load counts, less cognitive deficiencies, and better family support. Unexpected was finding that more youth in the high adherence group were exposed to violence. Also, youth in the high adherence group were more sexually active.
Programmatic Services

The University of Connecticut Health Center and the Connecticut Children’s Medical Program (UCHC/CCMC) is the main HIV program in the northeast part of the State. The program strives to provide integrated care in one place and delineate ways to facilitate provider collaboration. A multidisciplinary team of doctors, nurses, dental hygienist, nutritionist and social workers see the patient during a clinic visit. Because the clinics take place at the children’s hospital, primary care including gynecology and many other services can be offered in the same place. For the pregnant adolescents, services are offered at the Women’s Health Center at Hartford Hospital located on the same campus.

The social services unit is funded in large part by the Ryan White Care Act and consists of five social workers that make available an array of services such as: psychosocial support, case management, support groups, mental health counseling, secondary prevention education and HIV counseling and testing. The program is the primary provider of pediatric and adolescent HIV care for Hartford, Tolland and Middlesex counties and serves over 184 clients.

The program works closely with the Department of Children and Families (DCF). Sixty percent (18) of the families had been involved with DCF and in most cases received services from the agency. Although not all the services are the result of punitive action, families usually fear this agency’s intervention because it could mean family separation,
with the children going into foster homes or institutions. However, this agency has an array of programs that eventually can help the children and youth and it is very difficult for families outside of the system to obtain these services. The problem with this system is that their preventive services are mostly ineffective until the youth are committed to the State. Also, the system allows the youth to refuse services when they reach 16 years of age.

Although the program tries to provide comprehensive care, because of financial constraints, it lacks a mental health component that could provide neuropsychological testing for every youth or psychiatric assessment and long-term therapy so that many of the mental health problems would not go undiagnosed. To have a youth diagnosed, a crisis in the school or home needs to occur, but, very seldom does a diagnosis result only from a referral. Another problem is the lack of appropriate adolescent mental health specialists and this is worse if attention to culturally relevant concerns is needed. If the problems around getting a psychiatrist, psychologist or therapist are resolved, there remains the issue of whether the youth will participate. One of the biggest problems in getting youth to receive therapy is lack of motivation. For many youth, the only way they will go to therapy is if the court mandates it. Social workers try in many ways to provide this most needed service. They search for appropriate mental programs in the community, work with the schools and the families to obtain services through the school system or DCF, and they provide short term counseling in the clients’ homes. The best counseling sometimes has been done while shooting hoops, driving the youth to their homes or having pizza. Another successful intervention with a small number of
participants has been psycho-educational groups run by the social workers that combine emotional support with knowledge of the disease and recreational activities. Although coming to the groups reminds them about their condition and as a result they are sometimes reluctant to participate, these group meetings and the clinics are the only times/places when they can freely talk, cry, be angry, sad or even happy.

Transmission of the disease is a main concern in the program and all the staff work hard to encourage youth to disclose their status to their partner or partners. If the youth feels comfortable to tell the partner, the staff works with both of them providing education about the risks and risk reduction skills while testing the partner. If the adolescent is not up to the stage of disclosing, counseling is provided and if the name of a partner or partners is given, a referral is done to the CARE program. This program will contact the partner or partners and make them aware of the fact that they have been in contact with a HIV infected person and need to be tested. Disclosure is very difficult for adolescents; they fear rejection or physical aggression. If the young adolescent is going through a period of turmoil with the family, usually they are looking for a way out and getting involved with somebody who will provide a way out. In these situations, they are usually not prepared to disclose their diagnosis to any of their sexual partners.

Adherence to medications in adolescents is a major factor in their lives and changes according to their age, developmental stages, emotional status, relationships with their friends and the family situation. If adherence among these 30 youth is based on immunological classification, CD4 counts and viral loads, there would seem to be no
problem in this study. This is due in large part to the support provided by the program to ensure that the youth take the medications and the attention the program pays to the broader aspects that impact these individuals when taking their medications. Doctors and nurses make sure that each youth has the medical attention and tests needed such as genotype and phenotype to best monitor their condition and provide them with the most effective medications. The nurses are attentive to prescriptions and timely refills by working with the youths’ families and pharmacies to ensure this happens. There is a nurse dedicated to work with the youth having problems with adherence. Social workers facilitate access to health care by working with the government or private health insurance companies. Since 90% of the adolescents in the study have government insurance, the social workers work very closely with the families to stay current with all the regulations needed to keep the insurance active. They also facilitate access to the clinics by arranging transportation through the insurance covered medical services or from community resources. In addition, the social workers also must pay close attention to issues of poverty, mental health, education, housing, legal issues and dual and triple diagnoses that impact adherence. Overall, there is a conscious effort on the part of the team of providers to educate the youth about the importance of taking their medications. This educational process goes on in different ways; during clinical appointments, individual counseling, home visits and support groups.

Also, adherence outcomes in this cohort of adolescents may have been helped by the fact that five youth were in juvenile detention or mental health institutions where medications are given. Also there were four youth that were not taking medications
because their counts were not low enough to jeopardize their health. Three of them were youth with heterosexual transmission and because their immune systems were formed when infected it has allowed them to live without medication for some time. In addition, two of the female youth were pregnant at the time and they were very concerned about the importance of taking their medications to protect their babies from acquiring the HIV infection. During pregnancy, they are monitored closely to make sure they are taking the appropriate medication regimen to prevent the transmission of HIV to the baby. Communication with the OB Gyn provider is very important to keep them adhering to their HIV medication and to reinforce the education that the OB Gyn team provides to them. As a rule, those pregnant in the study have been very adherent to their medications.

Although adherence to medications in general has been very good, in some instances the lack of adherence was due to family disruption or other family issues, as in the cases below:

A mother wanted to protect her adopted daughter from discrimination in the rural community in which they lived; she did not allow the hospital staff to disclose the diagnosis until the teen found out by herself. The adolescent was so hurt by this deception that she became extremely angry towards her adoptive mother and very depressed and refused to take any medications. Although she stated that she hated the medication, the underlining issues were her anger and depression.
Working through this emotional response has been very difficult for her and has severely jeopardized her health.

Another parent with concealed mental health and family issues has not cooperated. She is an infected mother that does not take her own medications and also refuses to give child medication. This is an overwhelmed, depressed mother who is going through the process of a divorce, has two children, the oldest one diagnosed with cerebral palsy and the youngest with HIV and a chromosome syndrome.

The team’s commitment to maintain the health of these youth is intense. If an appointment is missed, there is immediate telephone follow up to find out the reason for not coming. If the phone call is not successful, a home visit will follow. In all, 77% of the youth rated their communication with the hospital providers as good, although some of them said that coming to the appointments reminded them of their HIV condition.

Chapter 5: Conclusion

On the important issue of medication adherence, causes for incomplete adherence, as much of the literature review and the program results showed, could particularly be due to the lack of knowledge about factors that presently affect adolescents. For some adolescents, mental health problems can adversely affect adherence. Depression in particular is a factor that is overlooked and under treated: other factors are lack of family
or family support, and homelessness, which for adolescents means being on the street or in shelters, or living with friends or frequently changing living arrangements with various relatives (none of these arrangement provides a stable environment that supports adherence). Lack of psychological evaluations in the school system does not allow sufficient attention to their behavioral as well as cognitive needs. Poverty limits comprehensive care. People with limited resources do not have access to appropriate mental health services, eye care, dental care, etc. In other instances, poverty means adolescents miss the basics, such as food and housing, or places them in situations where violence is a way of life. Some youth in the program are in greater danger of dying because of violence than from their HIV infection so adherence is the least of their concerns. We have learned that adherence interventions need to be tailored to the adolescent’s individual needs, accounting for their biological, psychological and social needs. These are continuously changing as the adolescent matures. Efforts to support adherence are often hindered by lack of knowledge about what supports adolescent adherence specifically and what will maintain adherence over time. Further studies are needed to learn more about adolescents and the way they adhere to medications. These studies should include social and environmental factors.

Pediatric and adolescent HIV is not disappearing and there is an urgent need to bring it to the public’s attention. In addition to the cohort of children who acquired HIV from their mothers, there are the adolescents who have been infected through sex or drug addiction. HIV has been a predominately minority disease and most of the infected adolescents live in deprived conditions. Many of these youths live in poverty, disrupted
families, and unfriendly environments and sometimes they have adopted unacceptable behaviors to survive. Often these issues are compounded by cognitive deficiencies, behavioral and mental problems. In addition to all these problems, HIV disease brings other burdens, especially stigma, regardless of how they acquired it.

While the number of babies with HIV infection has dropped dramatically, there is an increase in the number of adolescents acquiring HIV, mainly through unsafe sex. As a result, the overall picture of adolescent HIV will continue to be with us in the US through unsafe sex while mother to child transmission and adolescent acquisition of the disease throughout the world will be a growing reality. Care providers for adolescents with HIV must not only treat HIV but also these multiple and complex issues adolescents are facing.

It is a difficult task to address the problems of HIV youth given the inadequacies of existing systems. Looking at adolescent HIV as a whole, and taking into account the care for HIV infected youth and prevention for the adolescents at risk, there is much room for improvement. Many times in the planning for HIV programs and allocation of funding, adolescents’ needs are not considered because it is assumed that they can be covered in children or adult programs. This may have occurred because adolescence is a period of constant transition from childhood to adolescent to adulthood. Frequently people who plan and fund programs do not know how to assess youth needs or not want to deal with an agency’s bureaucracy. An example of this is when the Department of Public Health does a needs assessment and does not include youth because the process to
obtain the required consent forms to interview a youth under 18 years old requires adult consent as well.

If the care side is reviewed, the provision of medical care for HIV infected adolescents has been part of government guidelines. Nevertheless, there are areas that need more attention, including mental health, dental care and substance abuse treatment. Also, funding for ancillary services that make the care comprehensive (case management, transportation, housing, client assistance) has been threatened in the last few years. Existing medical programs dedicated to HIV positive adolescents have received more attention because they are based in hospitals and the medical providers are more aware of the adolescents’ transitions and needs. As seen in the literature review, medical providers advocate for, and participate in, research in order to provide the care HIV positive adolescents need.

On the other hand, HIV adolescent prevention has not enjoyed the same attention. Prevention efforts have been paramount in mother to child transmission with very good rates of success. The need to dedicate more attention to prevention in the adolescent population has been demonstrated by government agencies. Recent CDC reports have stated that half of the people who are infected but unaware of their HIV infection are young people (MMWR 2006). Also, The U.S. Department of Health Resources and Service Administration (HRSA) recognizes the need to find people who are infected, get them tested and linked to care. Based on these findings and recommendations adolescent
prevention should be at the forefront in program development and funding, but unfortunately it is not.

A combination of outreach and the use of new innovative technologies could achieve the desired prevention for adolescents at risk of acquiring HIV. Rapid HIV testing has made it easier to provide HIV testing in clinical and non-traditional settings. Also, rapid tests produce results in 20 minutes, allowing the person to have the test results in only one visit. Normally it has been proven that providing knowledge of the disease has not been enough to change behaviors that put people at risk of getting HIV but coupling it with results has a greater impact. Therefore, a number of behavioral science based interventions called DEBIs (Diffusion of Effective Behavioral Interventions) have been developed and recommended by CDC (MMWR 2006). In spite of all the technological advances and the knowledge gained, adolescent prevention at local and state levels has not reached the level required.

Since HIV infected persons are the source of infection for others, CDC has promoted prevention interventions with HIV infected persons. In 2003 CDC implemented “The Advancing HIV Prevention Initiative” (MMWR 2006), which formally adopted persons living with HIV as a core element in their prevention efforts. However, again, at the local level, specific interventions for HIV infected youth were not funded in the last prevention awards cycle.
Because of low funding levels overall prevention for at risk and HIV infected youth has been a low priority. The allocation of funding for very specific population interventions (DEBIs) has been the priority for prevention awards for adults to the detriment of funding for general outreach programs that were the ones who reached youth out of networks such as men having sex with men (MSM), school drop outs and the homeless.

This thesis has been a learning process. Applying the knowledge gained, the author has disclosed recommendations for an ideal program for an adolescent HIV program. An ideal program will encompass both care and prevention. In the area of care the services need to be integrated and provided at one site. Therefore, HIV and primary care that covers gynecology for the young female adolescents and similar care for the male youth will be provided in one visit as needed. Adherence to medication will be an important part of the care and based on individual assessment of the youth’s cognitive, mental, behavioral and environmental factors. It will be done through different means: the doctor, the nurse, groups or peer education and peer support. The medical and social work staff will train the peers. Since the program is located at a children and adolescent hospital or clinic, referrals for other medical needs will be taken care of by the specialties in the hospital. Mental health will be an intrinsic part of the program and will have a component with psychologist, therapist and case managers. Since the person that works closely with the adolescent is the case manager, who is a graduate social worker, this person will do the first assessment for mental health needs and provide the youth with a referral for therapy or neuropsychological testing if needed. The role of the case manger
as seen in the Montefiore Hospital program is crucial in making sure the youth receive the services they need. Case managers will advocate for them with the schools, courts and other needed services such as guiding youth through employment, post high school education, employment and living skills to help youth transition to adulthood.

A prevention component has to be built into the adolescent program. This prevention should have two parts, one for the HIV infected adolescents and the other for the youth at risk to acquire HIV. Prevention for HIV infected youth is a public health concern; therefore, it will be given special consideration. The whole team, medical and social work staff should work on a protocol that will include the assessment of the youths’ readiness to disclose their HIV status to their partner. Assessment for possible violence is very important and proper support will be given during the process. Counseling and testing will be offered to the partner or partners and risk reduction skills will be taught. If the adolescents do not want to tell their partner/s, a referral to the CARE program will be made.

Prevention for youth at risk will be done at the community level. This is a major effort that no agency can do alone. A consortium of agencies that can bring significant elements together and learn from each other will provide ideal outreach program. Important issues such as identification of cultural issues in African-American, Caribbean-American, Latino and Asian cultures is significant but overall, the adolescent culture is what cuts across all these cultures. The knowledge of how to approach cohorts of youth with specific behaviors common to all cultures, including heterosexual, MSM,
transgender, and drug addicted, play a central role in any prevention outreach activity. Information about other infections that put youth at risk of acquiring HIV such as sexually transmitted diseases (STDs) is also crucial in any prevention intervention. It will be most important to catch the attention of youth for the very serious issue of HIV and STDs testing and counseling.

The UCHC/CCMC program has created a model called Hartford HIV Identification and Linkage to Care (HYHIL) that has demonstrated ways to attract youth, but has not been able to achieve the goal of unifying all youth oriented agencies to create an adolescent prevention plan for the Greater Hartford area. The main barrier has been the lack of funding for adolescent programs for the agencies and for the coordination of the model.

Peer interventions have been proven effective in outreach. A project such as the one at UCHC/CCMC called Teens Against Negligence (TAN) trains adolescents infected, affected and at risk to be peer educators. These youth provide prevention education presentations to other peers and work in liaison with HYHIL to engage youth in the community prevention activities where HIV/STD testing and counseling is done.

Work on adolescent HIV is a worthwhile effort to help positive youth in their fight for a better life and to decrease the spread of the disease among youth at risk. All of these HIV infected youths are in some way or another the victims of this disease; it is imperative to continue helping them to obtain maximum achievement. There must be an
increased awareness of the special needs of this population. They must not to be treated as adults when their brains are still in development but as adolescents who are going through a child to adult transition. Systems need to be sensitive and aware of the changes of adolescence. Providers need to be caring enough to humbly accept and learn from the sometimes negative responses of these youth and recognize their struggles living with this disease.

As for prevention, until scientists find a cure, the communities and the government as planners and funders need to recognize that a main way to diminish the expansion of the epidemic is to pay attention to the youth at risk. The work in this field is intensive and urgent. HIV prevention needs to be more powerful at the beginning of the cycle of life. As much attention as was given to mother to child transmission, an even stronger effort is needed to prevent young people from getting the infection and being a source of new infections. It would be ideal if communities could unite the scarce financial resources and work together preventing the disease. It would be ideal if we could curb the sources that promote inappropriate behavior in young people. All of us lose if HIV continues its devastating course.
References


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U.S. Department of Health and Human Service: HIV Infection in Adolescents and Young Adults, NIAID Fact Sheet, May 2004

Appendix

HIV MEDICATION ADHERENCE AND PSYCHOSOCIAL FACTORS

QUESTIONNAIRE

Identification __________________ Age ______
Date of interview ______ ______ ______

SOCIO-DEMOGRAPHIC BACKGROUND

Gender:
Male ______
Female ______
Where do you live?
Hartford ______ Middletown ______
Manchester ______ New Britain ______
East Hartford ______ Other (specify) ______

Please mark the race/ethnicity you think you belong to:
African-American ______ Hispanic ______
White ______ Asian ______
Native American ______ Mix ______

Please indicate if any of the parents is dead:
Father Yes ______
Mother Yes ______
Both Yes ______
Living arrangements.

- Biological mother
- Father
- Relatives
- Adoptive Parents
- Transient
- Institution
- Self

Parent’s caregiver education:

- High school: Yes or No
- College: Yes or No
- Master: Yes or No

What type of housing do you live in?

- Own housing
- Rent housing

Sources of family income:

- Employment
- Government
- Both

Annual Income of household:

- Less than $10,000
- $10,000 - $20,000
- $20,000 - $30,000
- $30,000 - $40,000
- $40,000 - $50,000
- More than $50,000
Does your family own a car?
Yes ______ No ______

What kind of help do you receive?
Rent subsidy Yes ______ No ______
Energy assistance Yes ______ No ______
Food stamps Yes ______ No ______

How important is religion in your life?
Very important ______ Someway important ______ No important ______

Does your family belong to any organization?
Community Yes ______ No ______
School Yes ______ No ______
Church Yes ______ No ______
Volunteer Yes ______ No ______

What programs or service you and your family use in the community
St. Juan Center ______ Salvation Army ______
CRT ______ Hispanic Health Council ______
Catholic Family Services ______ Food Pantries (specify) ______
Dpt. of Social Services ______ Police Department ______
Artists Collective ______ Recreational Programs ______
Ryan White Network ______
DEVELOPMENTAL

What grade are you in school ______ not in school ______
If not in school what grade did you drop out ______
In the school what track are you in:
Honor _____ Academic _____ Adult _____
General _____ Special Ed. _____ Vocational _____
Have you had a psychological evaluation?  Yes _____ No _____
What grades did you have last year? Most of them were:
A’s _____ B’s _____ C’s _____ D’s _____ F’s _____
Other ____________________________________________
Have the mother/guardian been called to school because of problems?
Yes _____ No _____
How many times in the last year were you:
Detained _____ Suspended _____ Expelled _____
Have you been involved with DCF?  Yes _____ No _____
If yes, why ________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Have you or anyone in your family used any type of drugs or alcohol in the last six months?

<table>
<thead>
<tr>
<th></th>
<th>Alcohol</th>
<th>Marihuana</th>
<th>Cocaine</th>
<th>Heroine</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myself</td>
<td>1_____</td>
<td>2_____</td>
<td>3_____</td>
<td>4_____</td>
<td>5_____</td>
</tr>
<tr>
<td>Partner</td>
<td>1_____</td>
<td>2_____</td>
<td>3_____</td>
<td>4_____</td>
<td>5_____</td>
</tr>
<tr>
<td>Children</td>
<td>1_____</td>
<td>2_____</td>
<td>3_____</td>
<td>4_____</td>
<td>5_____</td>
</tr>
</tbody>
</table>
Has your mom, caretaker ever been in jail? Yes ____ No ____

Had any of your family ever been in jail? Yes ____ No ____
If yes, why

Have you been in any juvenile detention? Yes ____ No ____
If yes, why

Have you been in court? Yes ____ No ____
If yes, why

How many close friends do you have? # ____ None ____

Do you have friends of the opposite sex? Yes ____ No ____

Do you have a boyfriend/girlfriend? Yes ____ No ____

Are you sexually active? Yes ____ No ____
If yes do you use protection (condoms)? Yes ____ No ____

Does your partner know about your condition? Yes ____ No ____

Do you have more than one partner? Yes ____ No ____
If yes, how many 1 – 5 ____ 6-10 ____ 11 – 15 ____ 16 – 20 ____ >20 ____

What activities do you do with your friends?

Go to movies ______ Parks ______ Dance ______ Malls ______ Clubs ______

Talk ______ Drink ______ Use marihuana ______ Use other drug (specify) ______

Sell drugs ______ other (specify) ______

Have you ever been abused?

Physical Yes ____ No ____

Sexual Yes ____ No ____

Emotional Yes ____ No ____
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you ever been depressed for more than two weeks?</td>
<td></td>
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<tr>
<td>Have you ever run away?</td>
<td></td>
<td></td>
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<tr>
<td>Have you ever thought about running away?</td>
<td></td>
<td></td>
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<td>Have you ever been involved in a fight?</td>
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<td>Have you ever witnessed violence at home or in the community?</td>
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<td>Have you ever had suicidal thoughts?</td>
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<tr>
<td>If yes, do you have a plan?</td>
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<tr>
<td>Have you had professional help (counseling)?</td>
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</tbody>
</table>

Do you participate in any group in the community?

- Youth group
- Church group
- Community group
- Sport groups
- Art, music, theater group
- Volunteer group

How many friends know about your diagnosis?

What things make you happy?

Do you have a special person to share or talk when you are happy?

What things make you sad or depressed?
When your are sad, depressed or feeling low what do you do. Do you talk to somebody?

HEALTH CARE

What kind of health insurance you have:

Private ______ State ______

How many times have you been in the emergency room in the last 6 months?

0____ 1_______ 2_______ 3_______ more than 3_____

How many times have you been hospitalized in the last 6 months?

0______ 1_______ 2_______ 3_______ more than 3_____

The following statement is about your health and your health providers.

Please explain to the respondent the values attached to the scale and ask him/her to choose the value he/she thinks fit his/her family.

My communication with my doctor and nurse is:

Good |____|____|____|____| Bad

1 2 3 4 5

I trust my health providers:

Trust |____|____|____|____| Distrust

1 2 3 4 5

I follow up with the referrals for other doctors:

All the time |____|____|____|____| Never

1 2 3 4 5
Please say the name of your medication:

Knows: All _____ Some _____ None_____ 

I take the medications:

All the time _____ Sometimes _____ Don’t take meds _____

How many doses have you missed medications in the last 2 weeks?

0 _____ 1 _____ 2 _____ 3 _____ 4 _____ >5 _____

When do you miss most the medications?

AM _____ PM _____

What is the reason for missing medications?

Forget _____ Slept through _____ Away from home____ 
Depressed _____ Concern with disclosure _____ Don’t feel sick _____

Being in institution _____ Don’t take medication____

Do you understand the relationship between taking the meds & the lab results?

Yes _____ No _____

Youth source of infection:

Perinatal Yes _____ No _____

Heterosexual Yes _____ No _____

IVDU Yes _____ No _____

Transfusion Yes _____ No _____
OUTCOMES

Immunologic classification CD4:

N) No suppression (>500 CD4 )

A) Some suppression (500-200 CD4)

B) Severe suppression (< 200 CD4)

Viral load:

<table>
<thead>
<tr>
<th>Undetectable</th>
<th>200 – 1000</th>
<th>1000 – 5000</th>
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<tbody>
<tr>
<td>5000 – 10000</td>
<td>10000 – 20000</td>
<td>20000 – 50000</td>
</tr>
<tr>
<td>50000 – 100000</td>
<td>100000+</td>
<td></td>
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</tbody>
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