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Growing Up with HIV: Disease Management among Perinatally Infected Adolescents

Barbara J. Szelag
University of South Florida, bszelag@health.usf.edu

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Growing Up with HIV: Disease Management
among Perinatally Infected Adolescents

by

Barbara J. Szelag

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Anthropology
College of Arts and Sciences
University of South Florida

Major Professor: Linda M. Whiteford, Ph.D.
Julie A. Baldwin, Ph.D.
Heide M. Castaneda, Ph.D.
Stephanie L. Marhefka, Ph.D.
Nancy Y. Romero-Daza, Ph.D.

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DEDICATION

To my parents, Gladys and Daniel Szelag, who have redefined support and endurance. You have shown remarkable and loving acceptance of all of my adventures, quirks, tumbles, and choices, and have remained my rock. I kept at it because of you, and your love and encouragement made it happen and made it meaningful.

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TABLE OF CONTENTS

LIST OF TABLES	v
LIST OF FIGURES	vi
ABSTRACT	vii
CHAPTER 1: INTRODUCTION	1
Research Rationale.....	1
Situating the Research.....	4
Perinatal HIV in the United States.....	4
Perinatal HIV in Florida.....	6
Research Participants and Methodology.....	7
Purpose of the Research.....	8
Research Site.....	9
Research Questions	10
Research Hypotheses	11
Full Disclosure: Positionality and the Researcher	12
CHAPTER 2: LITERATURE REVIEW	13
Chronic Stigmatized Disease	14
Adolescence and Perinatally Acquired HIV Infection.....	22
Meaning, Identity, and Agency.....	23
Adherence to Medications	28
Family Dynamics	32
Health Care Relationships.....	34
Disclosure of HIV Diagnosis	38
Anthropology and Childhood Studies.....	44
General Conceptualizations	46
Childhood Studies and Management of Chronic Stigmatized Disease	49
Research Ethics: Ethics and Research with Children	57
Medical Ecology	63
CHAPTER 3: METHODOLOGY AND RESEARCH ETHICS.....	72
Role of the Researcher: Reflexivity and Positionality	73
Florida Family AIDS Network’s Perinatal Clients	77
Study Participants	79
Recruitment of Participants.....	81
Sampling	82

Limitation of Recruitment Process	85
Research Techniques and Data Collection	85
HIV-Positive Adolescents, N=17	87
FAN Data and Chart Reviews.....	87
Questionnaires.....	87
Semi-Structured Interviews	87
Clinical Care Providers, N=5.....	89
Semi-Structured Interviews	89
Biological Mothers of Perinatally Infected Adolescents, N=6	90
Focus Group.....	90
Data Analysis	90
Study Limitations.....	91
CHAPTER 4: RESEARCH RESULTS	93
Adolescent Data.....	93
Biological Mothers' Focus Group	96
Clinician Interviews.....	96
Results.....	97
Adolescent Engagement, Provider-Patient Relationship, and Adherence (Hypothesis 1).....	97
Adolescent Medical Knowledge	98
Medications.....	98
Labs and Viral Resistance.....	100
Provider Explanations of Medical Concepts.....	102
Summary of Adolescent Medical Knowledge	107
Adolescent Responsibility	108
Timing of Responsibility	109
Barriers to Responsibility	113
Summary of Adolescent Responsibility.....	115
Non-Adherence, Treatment Fatigue, and Treatment Interruption	115
Summary of Adolescent Engagement.....	120
Provider-Patient Relationship.....	121
Summary of Findings for Hypothesis 1	128
Family Dynamics and Peer Relationships (Hypothesis 2).....	129
Family Dynamics and Involvement.....	129
Support and Openness: Valerie, Jeff, Katie, and Mark....	129
Ambivalence and Silence: Zoë, Diana, and Stephanie	132
Effects of Stigma on Family Dynamics	135
Peer Relationships and Support	136
Culture and Stigma in Peer Relationships	136
Sexual Relationships and Disclosure	141
Clinicians' Discussions of Sexual Behavior	145
Support from Other HIV-Positive Adolescents	148
Summary of Findings for Hypothesis 2	149
Disclosure of HIV Diagnosis to the Child (Hypothesis 3)	150

Profiles: Earlier Disclosure of HIV Diagnosis.....	153
Jeff, 16.....	154
Paula, 13.....	154
Katie, 22.....	154
Nina, 17.....	155
Summary: Earlier Disclosure.....	155
Profiles: Later Disclosure of HIV Diagnosis.....	156
Diana, 19.....	156
Stephanie, 20.....	157
Sean, 20.....	159
Zoë, 16.....	159
Summary: Later Disclosure.....	160
Exceptions to Disclosure Age-Adherence Correlation.....	161
Lucy, 19.....	161
Keith, 18.....	162
Rachel, 16.....	164
Challenges of Disclosure: Biological Mothers.....	165
Summary of Findings for Hypothesis 3.....	170
Health Status and Adherence: The Illness Role in Chronic Disease (Hypothesis 4).....	170
Summary of Results.....	172
 CHAPTER 5: DISCUSSION.....	 175
Themes.....	177
Disclosure of the HIV Diagnosis to the Child and Caregiver	
Attitudes.....	177
Dominance of HIV as Social Phenomenon.....	185
HIV as Chronic Disease: Meaning, Identity, and Agency.....	189
Disclosure to Peers.....	193
Peer Relations.....	193
Sexual Relationships.....	195
Biomedical Implications and Provider-Patient Relationships.....	197
Stigma: An Underlying Theme.....	200
Additional Factors Complicating Adherence.....	202
Unexpected Findings.....	203
The Role of the HIV-Positive Researcher Revisited.....	206
 CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS.....	 210
Conclusions.....	211
Recommendations.....	213
Suggestions for Future Research.....	216
Coda.....	220
 REFERENCES.....	 222

APPENDICES	250
Appendix A: Adolescent Medication Questionnaire	251
Appendix B: Semi-structured Adolescent Interview Guide	254
Appendix C: Clinician Interview Guide	256
Appendix D: Focus Group Protocol	259
Appendix E: Codes for Analysis.....	262
Appendix F: Graphs of Adolescent Viral Loads.....	263
Appendix G: Graphs of Adolescent CD4 Counts/Percentages.....	269
 ABOUT THE AUTHOR	 End Page

LIST OF TABLES

Table 3.1	FAN Perinatal Clients	78
Table 3.2	Adolescent Participants.....	80
Table 3.3	Summary of Study Participants	84
Table 4.1	Study Participants and Adherence	95
Table 4.2	Adolescent Engagement and Adherence	99
Table 4.3	Adolescent Rating of Provider’s Understanding	121
Table 4.4	Sexual Activity.....	142
Table 4.5	Age at Disclosure and Adherence.....	152
Table 4.6	Biological Mothers in Focus Group.....	166
Table 4.7	Study Participants’ Disclosure by Caregiver	169
Table 4.8	Early and Late Disclosure by Caregiver	169

LIST OF FIGURES

Figure 1.1	Reported U. S. Perinatal AIDS and HIV Cases, 1985-2007.....	5
Figure 1.2	Florida Pediatric Cases by Diagnosis Year.....	6
Figure 1.3	Age Distribution of Persons Living with Perinatal HIV/AIDS in Florida ..	7
Figure 2.1	Global Distribution of HIV/AIDS, 2009	17
Figure 2.2	Persons Living with AIDS, by Ethnicity, United States, 2008.....	18
Figure 2.3	Rates of Infection by Ethnicity, United States, 2008.....	18
Figure 3.1	Current FAN Perinatal HIV and AIDS Clients.....	79
Figure 4.1	Keith’s Viral Load, 2008-2010	117
Figure 4.2	Keith’s CD4 Count and Percentage, 2008-2010.....	117
Figure 4.3	Sean’s Viral Load, 2008-2009	117
Figure 4.4	Sean’s CD4 Count and Percentage, 2008-2009	118

ABSTRACT

Children born with HIV in the 1980s and 1990s are surviving into adolescence and adulthood, due to the availability of highly active antiretroviral therapy (HAART). Growing up with a chronic and stigmatized disease presents considerable challenges as young people explore their sexuality, develop relationships, and take steps to become independent and productive adults. Adherence to HAART is an essential and life-long practice for the maintenance of health and longevity. For adolescents born with HIV, a daily medication schedule is one aspect of disease management that also includes medical visits, HIV status acceptance, bouts of illness, and disclosure of HIV status to others.

This research uses a framework of medical ecology to explore the personal, socio-familial, and medical contexts in which perinatally HIV-infected adolescents, as competent social actors, navigate the complexities of HIV disease management. It examines personal behaviors and attitudes, family dynamics, peer relationships, and health care structures and relationships that affect their adherence to HAART.

A key finding of this study was increased agency and adaptation to HIV among adolescents who learned their diagnosis earlier in life and whose caregivers demonstrated acceptance of HIV and support for the adolescents. They were able to adhere to their medication regimens, despite busy schedules, non-disclosure to friends, and treatment fatigue, and also had a somewhat better understanding of the medical aspects of HIV and HAART. Yet all of the adolescents had gaps in their understanding of clinical indicators and viral resistance, and the relationship between adherence and HIV transmission.

This deficit in a medical conceptualization and understanding of HIV and its ramifications is another important finding of this study. The adolescents' notions and actions regarding HIV disease, based on social, cultural, and medical norms and interactions within their environment, have a significant impact on the natural history of HIV. The level and consequent infectiousness of HIV as it responds to medications, mutates in their absence, and multiplies or is suppressed, depends on the individual's strict adherence to medications and attention to medical details, and affects HIV transmission to the individual's sexual partners. From both an individual medical and a public health perspective, an understanding of the ramifications of adherence and non-adherence to HAART is crucial. Early acceptance and understanding of HIV increase the possibility of successful medication adherence and overall disease management.

In order to facilitate perinatally-infected adolescents' disease management and adherence to medications, it is recommended that the process of disclosure of HIV diagnosis to the child begin early so that the child is fully aware by the age of ten. The acceptance of HIV in the family and clear-cut roles and responsibilities for disease management should be facilitated by ongoing instruction and counseling. Adolescents should be given thorough, if basic, instruction on the medical aspects of HIV, and should be encouraged to have friends, and especially sexual partners, accompany them to their clinic visits. This will encourage greater understanding of HIV and perhaps lead to less stigmatization of HIV and those living with HIV. Finally, providers and adolescent patients should construct a partnership in which their individual models of disease management are integrated and power and responsibility are appropriately shared.

CHAPTER 1: INTRODUCTION

Research Rationale

The development and availability of highly active antiretroviral therapy (HAART) have improved health and prolonged life for people infected with the human immunodeficiency virus (HIV). Children born with HIV in the 1980s and 1990s are now reaching adolescence and adulthood, something that was inconceivable before the advent of HAART and the highly effective class of drugs known as protease inhibitors. In fact, older children and adolescents are now the largest percentage of infected children (CDC 2009). Growing up with HIV poses complex problems as young people begin to explore their sexuality, develop relationships, and take steps to become independent and productive adults. Adolescence is a life stage fraught with change, growth, excitement, and confusion, and the added complication of a serious, chronic, and stigmatized disease presents huge challenges for youth as they grow and mature personally and socially.

Studies note that many HIV-infected adolescents have not been raised to learn the typical responsibilities of adolescence and adulthood, since more attention was given to making their presumably short lives as happy and carefree as possible (Wiener, Mellins, et al. 2007; Battles and Wiener 2002). Since the odds of survival into adulthood have improved, it is now critical to consider the special medical circumstances and social issues of young people HIV-infected since birth, in order to enhance their healthy development.

Adherence to HIV medication regimens is an essential and life-long practice for the maintenance of health and longevity. For adolescents perinatally infected with HIV, a daily medication schedule is one of many medical issues that also include regular medical visits, bouts of illness, developmental problems, acceptance of HIV status, and the ongoing decisions about disclosing one's HIV status to others. Living with a chronic, stigmatized disease is such a big challenge that parents and other caregivers often refrain from disclosing the diagnosis to the children for as long as possible. At the same time, as these children enter adolescence and begin to exercise independence and explore their sexuality, their need to be aware of and understand their disease intensifies. Since perinatally infected youth are generally receiving health care regularly, the health care setting is one venue in which their sexual health and development, responsible behavior, medication adherence, and disclosure of HIV status are addressed. Disclosure of status, both to an infected person and by an infected person to others, is a sensitive issue even for the individual who is equipped with the social, economic, and emotional resources to manage its consequences. For adolescents embarking on the exploration of relationships, sexuality, and independence, the issues of disclosure, acceptance, and responsibility related to HIV can be heavy burdens that affect their health behaviors, including medication adherence.

For perinatally infected young people, the development of autonomy, whether the emphasis is on separating from parents (loss) or on achieving independence (gain) (Beyers et al. 2003), is a complex issue affected by the "unexpected futures" (Domek 2006: 1367) they now have, and by the efforts of parents to keep them from the normal trajectory of growing up and from the knowledge of their disease (Battles and Wiener

2002). Autonomy as competence (Beyers et al. 2003) may also be challenged by a complicated family dynamic where one or more members are also HIV-infected and might die, or have died (Fielden et al. 2006). Knowing that AIDS has taken family members or severely burdens the family may affect how much the young person can believe in his own abilities to act, plan, and thrive (Steele et al. 2007:62). The identity-culture dialectic that defines adolescents presages their approach to disease management. Their responses, which are shaped by their “socioculturally mediated capacity to act” or agency (Ahearn 2001:112) in response to their HIV disease, become salient now that they are moving from childhood toward adulthood.

For perinatally-infected adolescents, this transition is complicated by the integration of an HIV identity from which they may, at times, distance themselves because they do not want to be associated with adults who were infected through stigmatized behaviors (Kang et al. 2008). The contradictory discourse of the child (Brannen 1996:115) as, on the one hand, a dependent and incompetent individual whose agency is ignored and, on the other hand, a child who is expected and encouraged to comply with medical instructions, points to the need for approaching the child, and especially the adolescent, as a more active participant or partner in the undertaking of tasks and construction of meaning normally thought of as resting in the adult domain.

The capability and level of participation or partnership in their health care must be evaluated for each adolescent. Maintenance of viral suppression has been problematic in adolescents with behaviorally-acquired HIV, and points to the need to evaluate adolescents for treatment readiness (Dodds et al 2003:44; Merzel et al. 2008:984), and better prepare teens with HIV for the life-long, sometimes difficult medication regimens

(Murphy et al. 2005). Perinatally-infected adolescents, while accustomed to taking medications, may nonetheless require similar groundwork as they become aware of their diagnosis and take control of their medication regimens. Since the effect of living with HIV since birth may be somewhat delayed maturity and treatment fatigue (Merzel 2008), this groundwork may result in the adolescent's taking control of her medications gradually or at an older age (Schwartz and Drotar 2006).

Because adolescents with perinatally-acquired HIV have been prescribed antiretroviral therapy from an early age, they are likely to have some resistant strains of HIV (Mullen et al. 2002). It is also possible that they were infected with a resistant strain carried by their mothers (Delaugerre et al. 2007). An additional, important distinction of HIV, among other chronic conditions, is that it is an infectious disease, and can be infectious even during long symptom-free periods. Moreover, the antiretroviral drugs are very unforgiving if not adhered to strictly (Fisher et al. 2006). For these reasons, adherence is extremely important; it makes a lower viral load and thus reduced risk of HIV transmission to sexual partners more likely, and it also reduces the risk of further resistance to the adolescent's current and future regimens. The adolescent's HAART and viral resistance history notwithstanding, it is of utmost importance for these adolescents to understand and practice good adherence, both for their own health and for current and future sexual partners.

Situating the Research

Perinatal HIV in the United States

In the United States, fewer and fewer babies born to mothers with HIV are themselves HIV-infected, due to more widespread HIV testing of pregnant women and

the administration of antiretroviral therapy to mothers and babies (Buchanan and Cunningham 2009). Figure 1.1 shows the increase and decrease of perinatal AIDS cases from 1985 to 2007 in the United States. With the advent of combination antiretroviral therapy and the development and availability of new medications, more reported cases were presenting as HIV-infected, having not progressed to AIDS. For this reason, the CDC began reporting HIV cases separate from AIDS cases in 1998, though the HIV numbers represent only those states that had instituted HIV case reporting (CDC 1998).

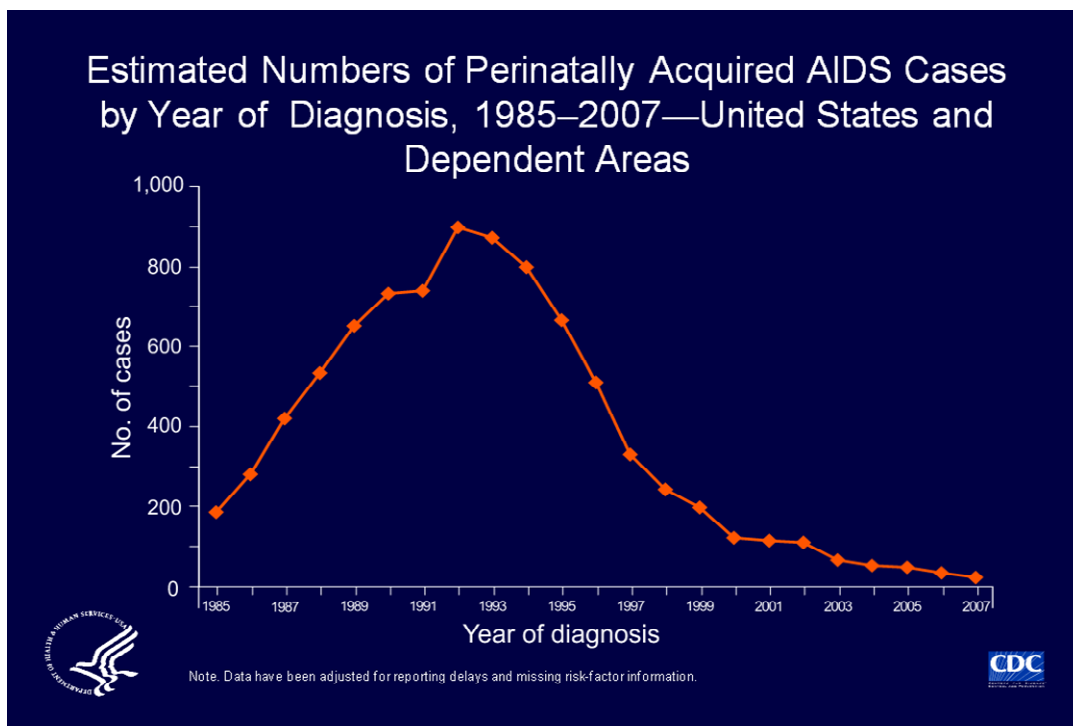


Figure 1.1 Reported U. S. Perinatal AIDS and HIV Cases, 1985-2007

Slide Source: cdc.gov

As of 2008, about 8,500 perinatal AIDS cases have been reported in the United States (CDC 2008). As of 2007, there were about 7,550 perinatally infected individuals believed to be living with HIV/AIDS (CDC 2008). Of these persons with HIV or AIDS, about one-third were under 13 years old (CDC 2008). Many of them are now expected to survive through adolescence and into adulthood. Thus, an understanding of how

perinatally-infected children and adolescents cope with HIV as they mature continues to be important for those providing services to them.

Perinatal HIV in Florida

In Florida, perinatal HIV infection rates have followed national trends. Figure 1.2 shows the cases of perinatal HIV/AIDS in Florida from 1977 to 2008. The perinatal transmission rate in Florida is now below 2% (FDOH 2009). Through 2009, there was a cumulative total of 2,356 perinatal HIV/AIDS cases in Florida, of which 76% were Black, 13% were Hispanic, and 9% were White (FDOH 2009).

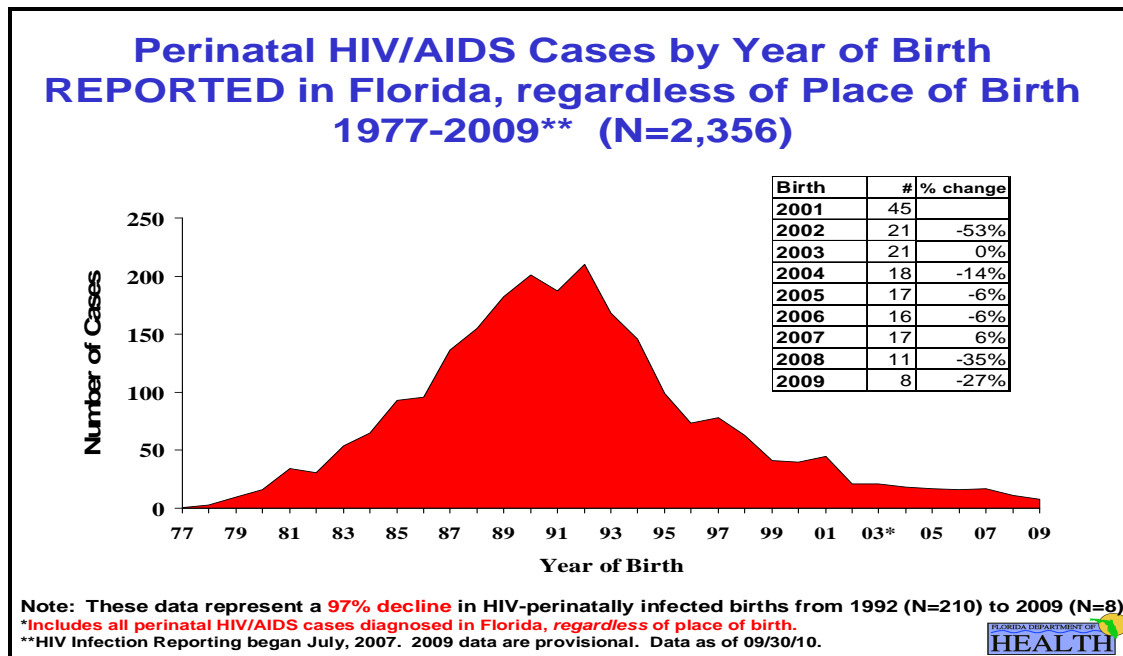


Figure 1.2 Florida Perinatal Cases by Diagnosis Year Slide Source: FL Dept. of Health

The increased life expectancy of person with HIV/AIDS is evident in the perinatally-infected cohort, among whom there are now individuals nearing 30 years of age. At the same time, there are currently between 550 and 600 children under the age of 13 living with perinatally acquired HIV in Florida. Figure 1.3 shows the distribution of 1,475 persons living with perinatal HIV or AIDS in Florida through 2009. Through

8/31/10, there were 1,479 persons with perinatal HIV/AIDS presumed to be living in Florida (http://www.doh.state.fl.us/disease_ctrl/aids/trends/msr/2010/MSR0910.pdf).

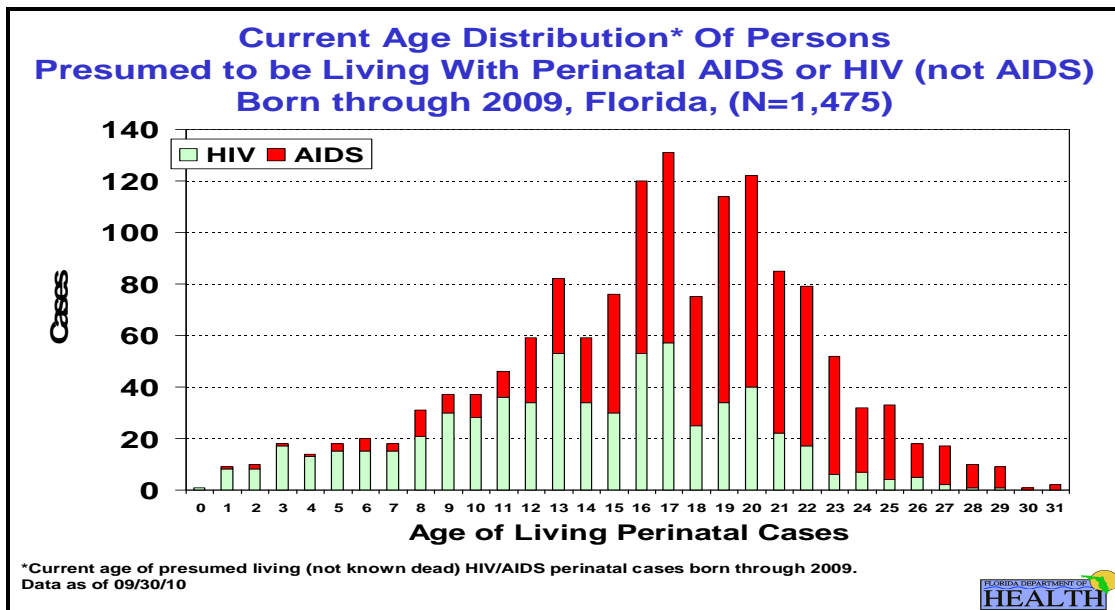


Figure 1.3 Age Distribution of Persons Living with Perinatal HIV/AIDS in Florida
Slide Source: FL Dept. of Health

Research Participants and Methodology

The participants in this research study were recruited from the Florida Family AIDS Network (FAN), a federally-funded program which targets and provides clinical and social supportive services for women, infants, children, and families infected and affected by HIV/AIDS. Seventeen individuals were enrolled from among the perinatally-infected adolescents aged 13 to 24 in FAN. A semi-structured interview was conducted with each adolescent, who also completed a short medication and adherence questionnaire. In addition, one focus group of biological mothers of infected children was conducted, and five clinicians who provide care to children and adolescents in FAN were interviewed.

Qualitative studies of medication adherence among people with HIV are underrepresented in the adherence literature (Beusterien et al. 2008; Sankar et al 2006).

The qualitative methodology used in this study of adolescents with perinatally-acquired HIV is an acknowledgment of the complexity of young people's lives, and the methods employed allowed a range of questions to be posed – not just what a person does, but why, how, where, and when (Lehoux et al. 2006:2092). This qualitative research allowed the young people to express themselves on issues that were of extreme importance to their lives and their health.

The study's focus on the perinatally-infected adolescent in his or her social and cultural environment is embedded in the theoretical frameworks of medical ecology and childhood studies. Medical ecology places the individual at the center of proximal and more distal contexts that interact with each other and variously influence the individual (Steele et al. 2007). The proximal niche has direct effects on the child's agency, meaning making, and behaviors, and childhood studies focuses on children as independent members of culture and society, with their own subculture and capacity to formulate meanings during their interactions within this subculture (Bluebond-Langner and Korbin 2007).

Purpose of the Research

Adolescence is the stage at which individuals begin to explore their sexuality and independence. Perinatally-infected HIV-positive adolescents are becoming sexually active and assuming greater responsibility for their disease management. Many adolescents with HIV are not engaging in safer sex and strict medication adherence, and this combination can increase the risk of HIV transmission to sexual partners (Letourneau et al. 2010; Quinn et al. 2000). In addition, adherence interruptions or medication refusal increases the risk of viral resistance and poorer health outcomes.

This research was designed to explore the personal, socio-familial, and clinical contexts in which perinatally infected adolescents navigate the complexities of living with HIV as they move toward adulthood and physical and emotional maturity. In particular, the study examined adolescents' medication adherence, and identified, compared, and analyzed personal behaviors and attitudes, family dynamics, peer relationships, and health care structures and relationships that affect their ability and willingness to comply with the instructions of their antiretroviral medication regimens.

These findings were used to propose measures that adolescents and their caregivers, medical practitioners, social service providers, and others in the adolescents' medical/ecological environment could implement to improve the health-related behaviors of adolescents. Recommendations for addressing the support, coping, and care of parents and other caregivers, the procedures and interactions of health care encounters, policy making, and ancillary service delivery were also proffered as a result of the findings of this study.

Research Site

The perinatally infected adolescents who participated in this research study were enrolled in the Florida Family AIDS Network (FAN), a program funded by a Ryan White Treatment Extension Act federal grant and administered at the University of South Florida College of Public Health. This grant targets women, infants, children, and families infected and affected by HIV/AIDS, and funds primary and specialty HIV care at five clinical sites and social supportive services at two case management agencies in the Tampa Bay area. The study participants were either patients at one of the clinics or received services at one of the case management agencies, and were specifically recruited

at the University of South Florida Pediatric Clinic in Tampa, Tampa Hillsborough Action Plan in Tampa, or AIDS Service Association of Pinellas in St. Petersburg.

Currently, FAN serves 163 clients with perinatally acquired HIV. Of these, 130 are between the ages of 13 and 24, and are categorized as adolescents. At the time of this study, 90 of these adolescents were receiving their care at the USF pediatric clinic, where the majority of the study participants were recruited. Two physicians and three nurse practitioners provided the clinical care for these adolescents, and they were interviewed for this study. Adolescents also had access to the services of a nurse educator, social worker, medical case manager, and licensed clinical social worker at this clinic.

Research Questions

Since it is essential that perinatally infected adolescents, like all individuals with HIV disease, follow a strict medication regimen to ensure continued health and survival, this study focused on adherence and its meaning in HIV disease management. The relationships between adherence and viral load and between viral load and HIV transmission risk also compelled an examination of adolescents' perceptions of risk with regard to sexual behavior. Therefore, the two primary research questions that this research addressed were:

Question 1: What factors obstruct or promote medication adherence for perinatally-infected adolescents? What cultural and social factors influence their decisions about adherence?

Question 2: How do perinatally-infected adolescents perceive adherence to their medication regimens?

A secondary area of inquiry involved adolescents' current and future sexual relationships and activity, and shapes the third research question:

Question 3: How do perinatally-infected adolescents conceive of and situate sexual activity and sexual relationships within their HIV disease management?

Research Hypotheses

The theoretical framework of medical ecology demands that the research questions be contextualized within the personal, social, cultural, and medical environments of the participants, and these contexts are assumed to have an impact on adherence behavior and sexual risk-taking behavior. Thus, the hypotheses that this study tested were:

H1: The active participation of the adolescent in his or her health care and treatment plan, and the level of trust in his or her health care providers have an influence on the adolescent's understanding of the importance of adherence and his or her acceptance of adherence responsibility.

H2: The lack of family stability (e.g., loss of parents or siblings to HIV) and peer support adversely influences adolescents' adherence.

H3: The timing and circumstances of disclosure to the individual have an impact on their subsequent adherence behavior.

H4: Health status has an influence on an adolescent's adherence. Very healthy or very ill individuals are more likely to stop taking their medicine, or to take it sporadically.

Full Disclosure: Positionality and the Researcher

This research was undertaken by an individual who shares the HIV diagnosis with her participants. My HIV-positive status was the motivating force behind my interest in and focus on HIV/AIDS in my academic and professional work. While my experience with HIV and disease management, from transmission risk and diagnosis to adherence and disclosure, has been different from that of the adolescents with perinatally-acquired HIV in this study, it was important to recognize my position of commonality with them regarding living with an incurable disease and attending to a daily medication regimen. My position as an HIV-infected individual allowed me to move into their HIV experience and back again into my researcher position, but it also had the potential to influence the relationships, analysis, and recommendations that were part of the research process. While it was not my intention to insert my experience and HIV identity into the research, I did remain cognizant of the standpoint from which I approached the research (Hendrick 2000). It seemed fair to allow both the study participants and any readers of the final research product access to this knowledge.

CHAPTER 2: LITERATURE REVIEW

HIV disease has become a chronic condition with the introduction and availability of highly active antiretroviral therapy (HAART). Like most chronic health conditions, HIV disease entails management that is life-long and physically, emotionally, economically, and socially burdensome. Added to these challenges is the continued stigmatization of HIV and its sufferers. For young people with perinatally acquired HIV, the ongoing and sometimes difficult medical management of the disease is coupled with the physical, cognitive, and social development of childhood and adolescence, which effects a challenging lived experience for the children themselves as well as for their families.

The role of anthropology in the study of HIV and AIDS has long been recognized in the development of “analytical perspectives which transcend conventional host-vector epidemiology” (El-Bayoumi and Morsy 1993:1). Anthropologists have engaged in research aimed at elucidating the meaning of AIDS in particular cultural contexts (Marshall and Bennett 1990) and the subjective experience of AIDS in different social and cultural environments (Alcano 2009; Whyte 2009). As HIV disease has evolved into a chronic condition in which individuals can experience long periods of good health, anthropological examination of the sick role (Crossley 1998) and clinician and patient’s differing chronic illness models take on added significance (Hunt and Arar 2001; Sobo 1999). For the perinatally infected children now entering adolescence and young adulthood, these constructed models of HIV disease, which encompass infectiousness,

prevention, and transmission, as well as ongoing care and treatment adherence, become salient as they endeavor to exercise agency as independent actors, especially in their intimate relationships (Hay 2010; Fernet et al. 2011).

Chronic Stigmatized Disease

While most chronic illnesses or conditions can be difficult to manage, due to their life-long and limiting sequelae, an illness, disability, or other condition that is chronic and also stigmatized can be demoralizing, and may require additional resources for effective management. It not only causes suffering in individuals with many different health conditions or disabilities, but it is complicit in reducing the effectiveness of the public health system in addressing and containing certain diseases, including AIDS (Van Brakel 2006: 307). There are many health conditions that, judged at the social level, impose a “spoiled identity” upon the sufferer (Goffman 1963), such as Hansen’s Disease (leprosy), epilepsy, AIDS, and various types of mental illness (for a review of the stigma of these and other conditions, see Van Brakel 2006). Numerous studies have been published on these conditions, and have enumerated the specific social obstacles that result from bearing the stigma of the disease. The inferior, disgraceful, or unacceptable qualities of a person with a stigmatized condition have been examined at an individual and micro-social level, which reveals the effects on and responses of the stigmatized individual (Link and Phelan 2001:366), but others have emphasized the social and cultural determinants of stigma (Kleinman et al. 1995; Link and Phelan 2001). Studies of the lived experience of the sufferer in his or her social and cultural environment emphasize both the varied manifestations of stigma and the interactionist and contextual underpinnings of stigmatizing attitudes and behavior (Moneyham et al.1996). It is crucial

to understand these influences on the lived experience of stigma in order to address the health-related responses that may stem from the stigma people feel or fear.

Stigma has been attached to a wide variety of actions and conditions other than illness (Link and Phelan 2001:363-4), but it has been extensively directed at a large and changing group of illnesses and disabilities over time (Sontag 2001; Van Brakel 2006). The attributes of, reactions to, and outcomes of the stigmatized condition have generally been negative, constraining, and segregating, both to the sufferers and to the social actors around them. There are typically four attributes that define a stigmatized condition: 1) the individual is responsible for his or her condition; 2) the condition is unchangeable or fatal; 3) there is a danger of contagion; and 4) the condition is apparent to others (Herek 1999:1105-6). While the latter three attributes have lost some legitimacy since the advent of highly active antiretroviral therapy (HAART), the first continues to have potency for people living with HIV (Lekas et al. 2006:1172).

The responses to stigma by the sufferers, particularly due to the cultural ideas of blame, punishment, immorality, taboo, and sin (Douglas 1991; Kopelman 2002; Nack 2002) that attach to their conditions, range from moral anxiety, guilt, and shame (Das 2001) to secrecy, denial, and isolation (Herdt 2001; Scambler 2009). The outcomes of these responses have personal and public health implications, which include ignoring prevention messages, delaying health care, developing other complicating conditions (opportunistic infections, depression, etc.), refusing to adhere to medication regimens, and increasing the chances of spreading disease (Carr and Gramling 2004; Weiss et al. 2006), in addition to the socio-political consequences, such as discrimination, exclusion, and violence (Herdt 2001; Nicolas and Schilder 1997). In addition to the effects of

stigma on those suffering from such conditions, stigmatizing attitudes can prevent the larger society from seeking health advice, practicing safe behaviors, and importantly in the case of AIDS, getting tested (Valdiserri 2002; Heijnders and Van Der Meij 2006).

While the focus of my research was on individual disease management, it is important to recognize that stigmatized diseases like AIDS have their roots in social structures of inequality and marginalization, and the unequal distribution of power (Farmer 1999; Lekas et al 2006; Parker and Aggleton 2003; Scambler 2006). In particular, the view of AIDS from its beginnings in the early 1980s has been one of a disease of outsiders and/or the powerless, invoking responses of “us” versus “them,” (Devine et al. 1999; Gilmore and Somerville 1994), in which AIDS does not concern the dominant, powerful majorities, but rather particular marginalized groups. The views of the powerful center maintain the social norms that stigmatize certain groups and certain conditions. Tewksbury and McGaughey refer to stigmatization as a “metaphorical vaccine” (Tewksbury and McGaughey 1997:53) since it is seen as “metaphorically removing or destroying its source” (Gilmore and Somerville 1994:1342). It is also conceived as an act of “symbolic violence” that reinforces the existing unequal social structure (Lekas et al. 2006:1166). In general, health is an important component of one’s identity, and is “sustained in part through the creation of ‘unhealthy’ others,” who are separate and dangerous (Crawford 1994). This attitude and the results of this social structure find their way into the identities and actions of those afflicted (Ciambrone 2003) and also into the relationships of stigmatized individuals with health care providers and with other institutional agents (Taylor 2001). The stereotypes associated with

stigmatized conditions are internalized by both the stigmatized and the stigmatizing (Fife and Wright 2000; Lekas et al. 2006: 1184).

The global distribution of HIV infection is heavily skewed toward the poorer nations (Parker 2002) and in the United States, HIV has disproportionately affected marginalized (Holtgrave and Crosby 2003) and minority populations, particularly African Americans (Oramasionwu et al. 2009). Globally, 90% of HIV/AIDS cases occur in the less developed nations, most in sub-Saharan Africa, where 80% of AIDS-related deaths have occurred (Bancroft 2001). Figure 2.1 shows the distribution of HIV/AIDS globally. In the United States at the end of 2007, African Americans accounted for almost half of all people living with HIV and 45% of new infections in 2006 (CDC 2010). Figures 2.2 and 2.3 illustrate the ethnic distribution of HIV/AIDS and rates of infection in the United States.

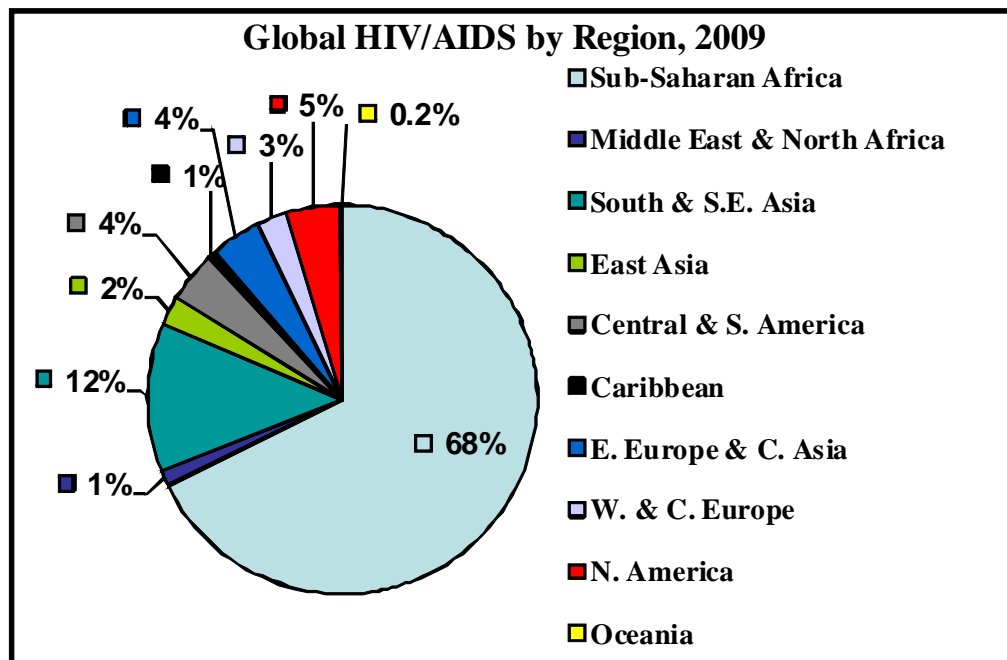


Figure 2.1 Global Distribution of HIV/AIDS, 2009

Source: who.int

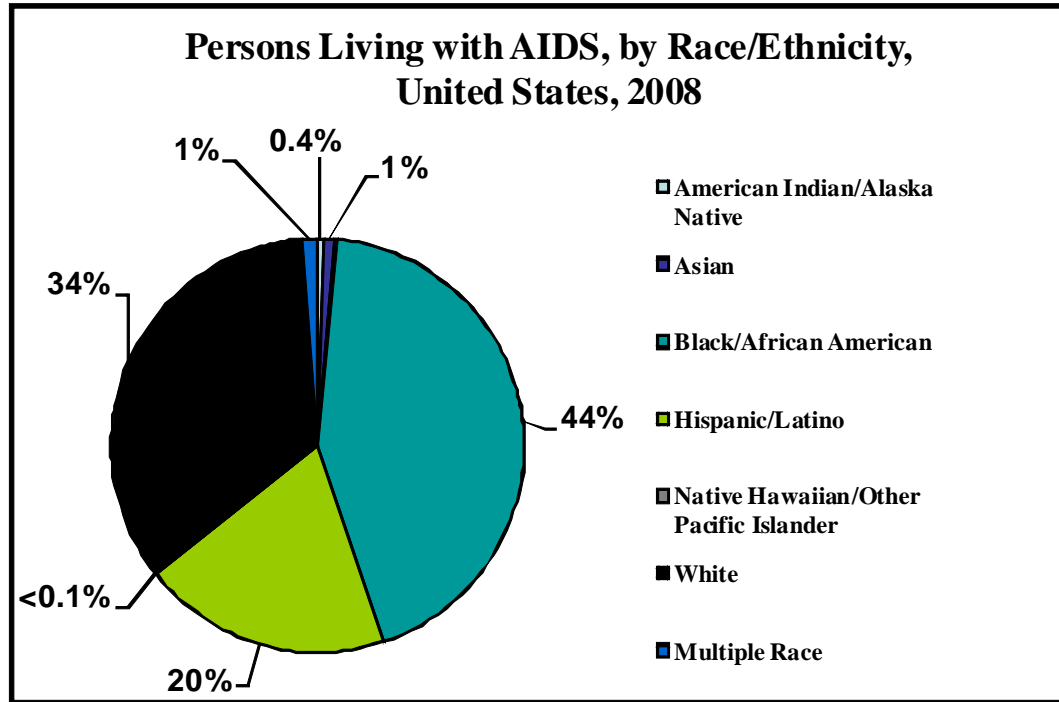


Figure 2.2 Persons Living with AIDS, by Ethnicity, United States, 2008
 Source: cdc.gov

The figure below illustrates the disparity in HIV infections among ethnicities by showing the rate of infection in each ethnic population.

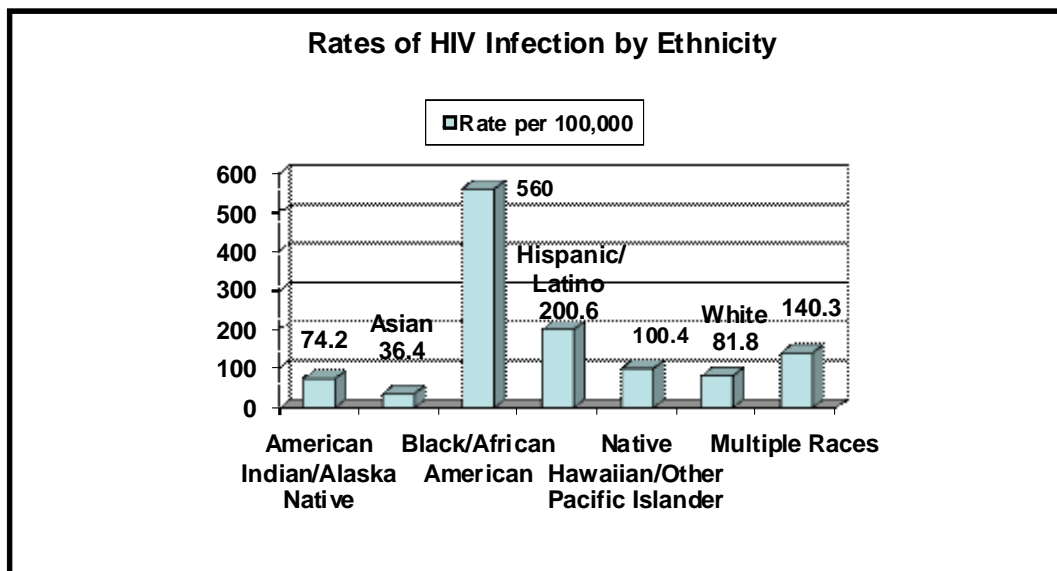


Figure 2.3 Rates of HIV Infection by Ethnicity, United States, 2008
 Source: cdc.gov

The genesis of this disproportionate burden of HIV in communities of color, and in particular, among African Americans, has been traced to a combination of factors that embed HIV risk in social, economic, and environmental structures (Lane et al. 2004). Residential segregation and high rates of incarceration have led to conditions in which concurrent sexual partnerships are common and women's power to negotiate their relationships may be diminished (Lane et al. 2004). This social organization increases the chances of HIV transmission. Disparities in health insurance coverage and access to health care have also been implicated in higher rates of HIV in certain ethnic communities (Chu and Selwyn 2008). Finally, social capital and income inequality have also been correlated with rates of HIV, where more social capital is associated with lower HIV rates and greater income inequality is associated with higher HIV rates (Holtgrave and Crosby 2003). Social capital has been variously defined and measured, but is essentially resources and benefits that result from social cooperation (Holtgrave and Crosby 2003; Beaudoin 2009). The benefits of social capital to health, however, have been shown to be mediated by income, and are significantly diminished among low-income Blacks (Beaudoin 2009). Thus, it is crucial to recognize and examine underlying socioeconomic conditions and their effect on health outcomes, including HIV transmission rates.

The social structural barriers to a good quality of life, parity in health care, and dignified treatment have led many with stigmatized CHC to challenge the status quo and foster the integration of their illness into their identity, undergo a transformation of ideals, and embrace a positive meaning of their condition in their lives (Thorne and Paterson 1998:175). The responses of stigmatized individuals are thus varied, depending

on their particular circumstances and possession of social and economic capital, and are “shaped by the relative power of the stigmatized and the stigmatizer” (Link and Phelan 2001: 380). The responses are personal and political, in that they are aimed at adapting to the personal circumstances of illness as well as resisting and challenging the societal norms that have made certain conditions moral and social burdens (Anspach 1979; cited in Taylor 2001). Many works have moved toward an examination of the opportunities for positive change, empowerment, transformation (Aujoulat et al. 2008; Mohammed and Thombre 2005; Farber et al. 2003; Baumgartner 2002), and “more optimistic analytic frames” that allow the person to maintain an unspoiled identity and anticipate a more affirmative future (Thorne and Paterson 1998:175). The theoretical perspective of chronic illness as a “biographical disruption” (Bury 1982) has been redirected in many studies toward thinking of chronic illness as more biographically integrative and adaptive (Carricaburu and Pierret 1995; Farber et al. 2000; Baumgartner 2002). Chronically ill people who are able to move beyond stigma and adapt to their illness can reconcile themselves to its presence and regain a healthy sense of body and self (Charmaz 1995).

Whether a chronic illness and its associated stigma are seen as threats or as opportunities, upon diagnosis or upon disclosure (in the case of HIV-infected children), people must confront this permanent presence in their lives. While they as individuals construct the meaning of their illness or disability, the meaning and the ensuing new illness identity, indeed any identity, “is shaped by external or social interactions” (Kralik et al. 2003:13), “both past and present social processes” (Fife 2005:2132). The incorporation of the illness identity has different effects on the lived experience and sense of self of the individual, and the identity can take different forms (Baumgartner 2007).

The illness identity may be paramount and embraced (Baumgartner 2007:920); it may be socially disruptive and require a renegotiation of identity status with others (Mathieson and Stam 1995). Some individuals will be their illness and others will consider the illness just one part of who they are (Bartos and McDonald 2000). The new identity may be maintained, altered, denied, suppressed, or surrendered to, but adaptation is considered a necessary part of coping with the condition and ensuring a quality of life and health (Charmaz 1995). The particular response to the chronic stigmatized disease is determined by the social and cultural context of the individual, and the meaning that he or she attaches to the illness and the particular mode of incorporation of illness into his or her identity will determine how he or she will manage the everyday aspects – medical, social, personal – of the disease (Bartos and McDonald 2000). It is important to examine the factors that allow and facilitate the incorporation of the illness identity and the adaptation process in ways that promote a positive outlook in the present, one that allows for the realistic anticipation of the future through the setting of goals (Schwartz and Drotar 2006).

The variation in adaptive measures taken toward the presence of a chronic disease necessitates an exploration of the variation in the cultural context of the individual and in the social environment in which he or she acts and interacts. The cultural context, including the beliefs and norms surrounding illness, influences the particular meaning that a person develops and attaches to his or her illness (Fife 1994:310). An understanding of the particular sociocultural variables which encourage and support “found meaning,” that is, a positive explanation that reconciles “the world view and the self view” (Thompson and Janigian 1988, cited in Fife 1994:310), is important for

disease management, since it is the adaptation to and acceptance of the chronic condition that facilitates the fulfillment of ongoing medical requirements, including regular medical visits and adherence to medications and other medical directives. The discovery of meaning and the incorporation of the illness identity, however that is manifested, into the self, are tasks requiring effort that may be especially challenging for adolescents, since they are developmentally at the point where they are grappling with the identities that will constitute their adult selves.

Adolescence and Perinatally Acquired HIV Infection

Perinatally-infected adolescents are embarking on a new phase both in their lives and in the “trajectory” (Alonzo and Reynolds 1995:303) of their disease. Though they have lived their entire lives with an illness that requires frequent medical visits and daily medication, many of them are just learning their diagnosis as they enter adolescence. For these adolescents, the ill self is habit (Charmaz 2002), but the HIV-positive self is not. While perinatally-infected youth are familiar with illness, that is, the lay experience of being sick, it is only upon disclosure that they are really able to confront their disease as a clinical phenomenon (Kleinman et al. 1978). This knowledge will then change the illness experience. This new information, as well as the new phase of adolescence, elicits responses to the illness: making sense of their disease (meaning making), integrating an HIV identity into their emerging adult selves, and exercising agency as increasingly independent persons. With this new knowledge, they confront the cultural definitions of HIV and AIDS, which now pertain to them. They must embark on a quest to discover what HIV means to them, and in a culture where the definition of AIDS provokes stigmatizing associations and labels (Kang et al. 2008; Rao et al. 2007), the quest for

meaning, identity, and agency may be arduous and psychosocially demanding (Battles and Wiener 2002; Dodds et al. 2003; Kang et al. 2008).

Meaning, Identity, and Agency

Meaning making, identity development, and agency all occur within the context of people's cultural systems, which in turn "are human creations, continually recreated and reimagined by individuals with diverging experiences and motives" (Buckser 2008: 168). Meaning is an individual dynamic construction that is embedded in the person's particular social and cultural context (Fife 1994:315; Thorne 1999:400), so the ill person may assign different meanings to the illness as his or her experience varies in changing contexts. The meaning of illness refers to the individuals' "unique perceptions of the world as they know it and the ways in which they perceive the [illness] event redefining their world, their place in that world, and therefore their personal identity" (Fife 2005: 2133). Fife's (1994:311) schema of meaning construction in the face of illness integrates these questions of meaning, identity, and agency which individuals face when they learn they have a serious illness, and she further argues that meaning comprises two conceptualizations, self meaning and contextual meaning, which are dialectically related (Fife 1994) and allow individuals to situate their illness experience in a context that gives their illness identity and social situation integrity.

Fife (1994; 2005) is cited in some detail because her conceptualization of meaning in illness provides a framework for attaching meaning to the illness both as personal, lived experience and as socially and culturally constructed event. The personal meaning becomes the basis for the establishment of a new, added, or changed identity, and this meaning is influenced by the meaning attached to the condition in the wider

sociocultural context. Further, if we conceive of culture as shifting rather than static (Taylor 2007), then it not only influences but is influenced by the personal meanings and lived experience of its members, as they go about “the remaking of moral meanings and the reframing of the ontology of suffering” (Kleinman et al. 1995:1321). This dialectic may be particularly salient in the case of highly stigmatized conditions, like AIDS, as members of a social and cultural community assume a “flawed identity” (Hosek et al. 2002:356) because of stringent negative cultural definitions and connotations, but may then contest the outsider status that this identity imposes in an effort to foster cultural change and resume normal, accepted membership status.

The meaning of a chronic, even stigmatized, condition can be positive or negative, and is unique to the individual, conditioned as it is by personal attributes, social factors, and experience (Kang et al. 2008:232). Since the factors influencing meaning making are variable, meaning can change (Thorne 1999). For adolescents with perinatally-acquired HIV, the factors that shape the meaning of HIV, in addition to stigma, include the life-long nature of their illness, the time and manner of disclosure, the secrecy and fear surrounding the illness, the burden of HIV on other family members, family loss, social capital (Sawyer et al. 2007:1485), delayed development, economic and other social problems, and membership in or association with marginalized populations (Domek 2006; Fielden et al. 2006; Hosek et al. 2005; Kang et al. 2008; Ledlie 2001; New et al. 2007; Rehm and Franck 2000).

The coalescence during adolescence of culture, identity formation, and the onset of autonomy will have a marked effect on how HIV-infected adolescents manage their disease. Culture describes not only the beliefs and values that are attached to health and

illness in general and to HIV in particular, but also to the symbolic interactions that the adolescents engage in with peers, family, community, and health care system. Identity includes, in addition to a myriad of roles vis-à-vis others, the HIV/AIDS identity (Baumgartner 2007), because HIV disease will always be a part of the adolescent's life. How the person integrates this disease identity will have an impact on how he or she responds to the medical factors involved in lifelong disease management – adherence, disclosure, illness episodes, medical routines, and overall attention to healthy living. The development and incorporation of the illness/disease identity also has implications for psychosocial wellbeing.

For any adolescent, the construction of meaning and identity is novel and potentially confusing. For the adolescent with HIV, as with other chronic illnesses, identity development can be negatively impacted by the illness (Hosek et al. 2002). Perinatally-infected adolescents nearing adulthood have been shown to have difficulty with their HIV identity because they do not want to be associated with the adults who were infected behaviorally through stigmatized behaviors such as drug use or homosexual activity (Kang et al. 2008). The denial or avoidance of the HIV identity is one of the stages of the developing adolescent identity, where one has not explored, acknowledged, or accepted the HIV identity as part of the self (Hosek et al. 2002). The individual at this stage of identity development, when he or she has not yet adjusted to the illness identity, manifests a coping strategy that is emotion-centered (LeBlanc et al. 2003), whereas adolescents at the other end of this identity development continuum exhibit problem-centered coping (LeBlanc et al. 2003), and have reached an acceptance of their HIV identity that allows them to think more about the future (Hosek et al. 2002).

Denial or avoidance coping has been shown to have negative consequences on both physical and mental health among adults, adolescents, and children with chronic illness (Dahlbeck and Lightsey 2008).

It is also important to note that the illness identity may be more salient at certain times. As with adults, adolescents find that their illness, as well as their life experience in general, takes center stage at certain times and fades into the background at others. Paterson's (2001) metastudy of chronic illness experience, revealed that illness and wellness perspectives can and do switch places, with illness coming to the fore as a result of mitigating medical or social circumstances. When the circumstances change, the wellness perspective may shift forward. Whether the illness or the wellness perspective dominates any given time depends not only on aspects of the illness, but also on the salience of socioecological circumstances, such as poverty, racism, violence, family problems, and stigma (Kang et al. 2008). Adolescents with perinatal HIV have shifted between periods of illness and periods of wellness throughout their lives, but it is during adolescence that their psychosocial, developmental, medical, and family changes will affect their own approach, not their caretakers' approach, to their illness. The shifting perspectives of illness/wellness during the confusing time of adolescence influence the decisions that these young people are now beginning to make for themselves. This shifting identity will have implications for whether, when, and how adolescents comply with medical directives, including medication adherence, discussed in greater detail below.

For perinatally infected young people, the development of autonomy is a complex issue affected by the "unexpected futures" (Domek 2006:1367) they now have, and by

the efforts of parents to delay the normal course of growth and maturity as well as knowledge of their disease (Battles and Wiener 2002). Autonomy as competence (Beyers et al. 2003) may also be challenged by a complicated family dynamic where one or more members are also HIV-infected and might die, or have died (Fielden et al. 2006). Knowing that AIDS has taken family members or severely burdens the family may affect how much these young people can believe in their own abilities to act, plan, and thrive (Steele et al. 2007:62). The identity-culture dialectic that defines adolescents presages their approach to disease management. Their responses, which are shaped by their “socioculturally mediated capacity to act” or agency (Ahearn 2001:112) in response to their HIV disease, become salient now that they are moving from childhood toward adulthood.

Ahearn’s pared down and direct definition of agency fits well with adolescents whose independent actions and the reasoning behind them are now taking shape. The cultural influences around them contribute to their construction of the meaning of HIV and to the identity they are developing in the face of this chronic, stigmatized disease. These influences, coupled with the particular HIV identity that has emerged, will determine the types of actions they take in dealing with their disease. Two of the more problematic areas of the adolescent experience of living with a chronic condition are the social stigma attached to their condition and anticipating and preparing for the future (Kang et al. 2008; Rehm and Franck 2000; Schwartz and Drotar 2006). Adolescence is a stage during which individuals value normalcy and want to fit in and establish independent social relationships (Fielden et al. 2006; LeBlanc et al. 2003). It is also the time of nascent independence when young people begin to make decisions that have the

power to affect their futures. They are aware of growing up and becoming adults, so part of their focus is on that future adulthood. These challenges – stigma and future goals – significantly shape and are shaped by the chronic disease experience during adolescence, and translate into agentic¹ decisions about and patterns of adherence and disclosure (Kang et al. 2008).

Adherence to Medications

Stigma is one of the cultural notions that, in Ahearn's (2001) words, mediate the capacity to adhere to medications and to disclose one's status to others. The negative effects of stigma lead to non-adherence and failure to disclose because secrecy is seen as the best defense against stigmatizing attitudes and actions (Brown et al. 2000; Rao et al. 2007) and the surest way to appear normal. Preparation for adulthood and the setting of goals, which adolescents begin to address independently, may be a source of ambivalence for youth with perinatal HIV, because they may not been raised with an eye on the future and they may have witnessed shortened futures in the death of a family member (Brown et al. 2000; Merzel et al. 2008). This uncertainty of the future may lead to difficulties in the transition to adulthood (Battles and Wiener 2002; Hosek et al. 2002) and affects how they perceive and manage adherence. In addition, if adolescents live with biological mothers, then their problems with adherence may reflect the mother's own difficulties in accepting her disease and taking medications every day (Cunningham et al. 2006:44). On the other hand, if a child's mother has a positive attitude about the future and the medications that make that future possible, this, too, may be felt by the child (Hammami et al. 2004).

¹ I opt for Ahearn's choice of the adjectival form of agency (Ahearn 2001:110)

The capacity to act in response to one's HIV disease is noted consistently in the literature as being affected by the medical ecological context of the young person (Brown et al 2000; Williams et al. 2006; Steele et al. 2007). In addition to stigma and personal constructions of the future, the agency of the adolescent with perinatal HIV within the domain of HIV disease management is influenced – either facilitated or constrained – by local meanings, that is, the culture of HIV (Brown et al. 2000; Baumgartner 2007), HIV medications (Belzer et al. 1999), family dynamics (Pontali 2005), the health care system (Dodds et al. 2003), and health care relationships (Pontali 2005). Medication adherence is highlighted in HIV disease management because it is currently the only action shown to improve and extend a person's life, but even more importantly, because HIV medications are very unforgiving if adherence is not virtually perfect. The risk of HIV resistance to medications escalates when patients fall below 95% adherence (Veinot 2006:265). This is equivalent to forgetting a dose fewer than two days a month. In the clinical tradition, adherence to HIV medications is essential and may seem incontestable, but clinicians often fail to recognize that “pills have symbolic power in addition to active ingredients” (Trostle 2000:40). The cultural background of the adolescent and his or her family and community determines the goals that are set with regard to managing his or her disease (Schwartz and Drotar 2006), and may not coincide with the health care provider's goals for the patient. Anthropologists have examined how differences in the provider and patient's understandings of illness and disease influence both health care interactions and the patient's health behaviors (Hunt and Arar 2001; Wong and Ussher 2008).

Non-adherence to medications may be intentional or unintentional. Bauman (2000) outlines the risk factors for chronic illness in general. While unintentional non-adherence seems to be more prevalent, HIV-positive people do sometimes make the decision to stop their medications. Perinatally-infected adolescents may be especially unwilling to continue taking their medications, because of the disruptiveness of the regimen and because they are weary of both taking the medicine and enduring the side effects (Bauman 2000). Unintentional non-adherence is more complicated – and more dangerous for people with HIV – because many factors outside of the individual interfere with the desire or at least the willingness to adhere. Adherence has been shown to be poorer among adolescents than among adults and younger children (Merzel et al 2008: 977).

The illness identity that incorporates meanings and values, and the disease management informed by this identity, develop in and are shaped by several contexts: the personal (cognitive, emotional), the social, the cultural, and the medical. Adherence, specifically, is dependent upon the adolescents themselves, their family and peer group dynamics, the medical aspects of HIV disease and highly active antiretroviral therapy (HAART), and the health care system and provider relationships (Pontali 2005). For adolescents just beginning to take control of their medication regimens, adherence as a patient-centered activity requiring active personal effort can be an onerous task. On the individual level, depression has been associated with non-adherence to HIV medications (Murphy et al. 2005). One of the factors that may predispose perinatally-infected children and young people to depression and other psychosocial distress is the loss or the threat of loss of family members to AIDS. In addition to the difficult adjustment after

such loss, there is the added burden of “disenfranchised grief,” during which stigma keeps children from speaking openly about the reason for their parent’s or sibling’s death (Battles and Wiener 2002:162).

Maintenance of viral suppression has been problematic in adolescents with behaviorally-acquired HIV, and points to the need to evaluate adolescents for treatment readiness (Dodds et al 2003; Merzel et al. 2008), and better prepare teens with HIV for the life-long, sometimes difficult medication regimens (Murphy et al. 2005). Perinatally-infected adolescents, while accustomed to taking medications, may nonetheless require similar groundwork as they become aware of their diagnosis and take control of their medication regimens. Since an effect of living with HIV since birth may be somewhat delayed maturity (Sherr et al. 2009), this groundwork may result in the adolescent’s taking control of his or her medications gradually or at an older age (Schwartz and Drotar 2006).

For some young people, taking medications reminds them of their HIV status or seems unnecessary since they feel well (Murphy 2003). Taking medications for an incurable disease may also elicit thoughts of their own, perhaps imminent, death, which is psychologically and emotionally daunting for a teenager (Dodds et al. 2003). The perinatally infected have the added menace of medication fatigue (Merzel et al. 2008). As mentioned earlier, an emotion-centered response to HIV may lead to poorer adherence. Finally, a huge problem noted by many young people is a logistical one, in which schedules and activities lead them to forget, not have medications with them, be unable to take them because they were busy, or not want others to see them taking their medications (Murphy et al. 2003).

In terms of the medical aspects of HIV and HAART, the chronic nature of HIV disease management may begin to affect the perinatally-infected adolescent's sense of normalcy. Disease symptoms and opportunistic infections that require hospitalization may be a fact of life, and the complexity and tolerability of the medication regimen and frequent medical appointments and directives may interfere with the individual's activities. As adolescents develop autonomy, they may express opposition to care and treatment by resisting caregivers' oversight (Merzel et al. 2008) or by rebelling against doctors' orders (Hammami et al. 2004; Veinot et al. 2006). Those adolescents with a sense of control over their health behaviors tend to achieve better adherence (Hammami et al. 2004). In particular, since they will have already been on medications for years as they reach adolescence, there is the possibility that they have changed regimens more than once due to treatment failure, and the current regimen may be complex and difficult. HIV medication regimens are generally composed of at least three different drugs, and may involve complicated scheduling. Adverse effects may also be severe enough to interrupt normal day-to-day activities, and will be a reason to forgo a dose (Belzer et al. 1999). While forgetting pills, whether intentionally or unintentionally, may be due to the young person's developmental abilities, it may also be the result of the "lack of compatibility of the antiretroviral regimen with daily activities" (Pontali 2005: 140).

Family Dynamics

The unique characteristic of HIV disease for the perinatally-infected child or adolescent is its presence in the family – an infected mother, and possibly also a father and siblings with HIV. Like genetic conditions transmitted from parent to child, perinatal HIV causes guilt, but unlike other transmitted diseases, HIV can and often does leave the

infected and uninfected child orphaned or with a mother compromised by the disease (Lee and Fleming 2003). There is also the family experience of stigma that accompanies an HIV diagnosis (Bogart et al. 2008), as well as the social and economic inequalities that underlie the HIV experience in many families (Castro and Farmer 2005). For this reason, there are many family configurations for the perinatally infected child – living with biological parents, foster parents, related kin, such as grandmothers, and adoptive families (Linsk and Mason 2004; Theall et al. 2004; Cohen 1994; Caldwell et al. 1992). The family situation has implications for the adolescent's success at adherence, because it introduces complex dynamics between infected members and between infected and non-infected members (Rehm and Franck 2000).

The relationship between the adolescent and his or her parent or other caregiver has an influence on how he or she will adhere to medications. An HIV-positive parent's attitude toward his or her own adherence may be important for how the adolescent adapts to this aspect of disease management (Pontali 2005; Williams et al. 2006), and studies have shown that HIV-positive caregivers' own adherence to medications and retention in health care may be affected by their attitudes toward medications, distrust of health care institutions, and poor relationships with their health care providers (Beer et al. 2009; Beach et al. 2006). Thus, the family's overall attitudes toward their health care must be explored.

Strategies and “adherence partnerships,” in addition to open communication, facilitate adherence in the sometimes hectic schedules of daily living (Merzel et al. 2008:981). Open communication between caregivers and health care providers can also have a positive effect on the young person's adherence, and the inclusion of family

members in the management of disease is vital from some cultural standpoints (Brown et al. 2000). At the same time, culture at the family and societal level may dictate secrecy and silence when it comes to a child's knowledge of his or her diagnosis and involvement in his or her health care (Lipson 1993; 1994). Studies show that biological parents differ from unrelated caretakers in how they transfer responsibility and disclose the diagnosis to the child (Ledlie 1999). A family-centered, multi-disciplinary approach acknowledges the importance of the family and the culture of the patient, and has shown positive impact on disease management (Brown et al. 2000:85).

The relationship of the primary caregiver to the HIV-infected child (Ledlie 1999), the social environment and support of the family (New et al. 2007), and the cultural beliefs that guide behavior all influence how an adolescent learns of his or her HIV diagnosis, and adjusts to the responsibility for his or her health and adherence to medications (Bikaako-Kajura et al. 2006).

Health Care Relationships

The final influence on HIV management and medication adherence is the health care system and the practitioner-patient relationship (Hammami et al. 2004; Pontali 2005). The health care system can be a convenient environment to navigate or it can confound the patient at every turn (Dodds et al. 2003), and the degree of availability, accessibility, affordability, and cultural appropriateness of health care services determines the degree to which patients are able and willing to comply with medical counsel. For the adolescent transitioning from pediatric to adult care, the new health care system can provoke considerable anxiety and lead to suboptimum compliance or falling out of care (Wiener et al. 2007). A transition team made up of clinical and psychosocial

practitioners, family members, and the adolescent can ease the move to adult care by engaging in planning and counseling with the young person before the transition occurs (Kang et al. 2008; Pontali 2005).

The adolescent's health care team is crucial to the success of the young person's management of HIV disease, both by providing the necessary information for correct adherence to often complicated regimens and by providing the support that young patients need (Pontali 2005). Perinatally-infected patients have been in care throughout their lives, and the relationships they have with these team members can be some of the more stable relationships in their lives. However, as the children moves into adolescence, the health care provider may also be viewed as the authority who poses demands on them and, from this perspective, does not acknowledge their lived reality and leaves them with no control over their actions. This position of the health care provider can be a huge barrier to adolescents' successful disease management (Dodds et al 2003:43).

The expression of agency as a form of resistance to collective representations (Das 2001) of a particular chronic health condition is one way that afflicted persons can cope with their condition, especially if it carries stigma, and can gain a measure of control that seems to be in the hands of society and the health care system. Agency as resistance can be directed at stigma, and thus lead to better adherence and disclosure, since individuals contest the stigma and act as valuable beings, without shame. Conversely, agency can be exercised as resistance to compliance and adherence, as patients attempt to gain a sense control that too often seems situated with the practitioners and with the medications that interrupt their lives (Kourrouski and Lima 2009; Childs and Cincotta 2006). Responses to this resistance can be found in refining compliance issues

so that the patient shares the decision making with the practitioner. This means involving the young person in the design of his or her care. Adherence and other management issues are fluid (Williams et al. 2006), as are the illness/wellness identities (Paterson 2001), and these vary according to the adolescent's personal and social concerns, as well as his or her medical issues. Health care providers must recognize that adherence may sometimes sink low on the list of an individual's priorities, and it is in collaborating on setting medical goals (Schwartz and Drotar 2006) that conflict between compliance and other lived experiences can be minimized. Adherence in adolescents seems to be positively affected by a warm, trusting relationship with their health-care providers (Pugatch et al. 2002).

The establishment of goals by the growing child may not have been encouraged by family or health care providers when survival beyond childhood was not probable. Now that children are becoming adolescents, and adolescents are becoming adults, it may be helpful to approach compliance as empowerment (Aujoulat et al. 2008), so that the young people feel that they have a stake in their health care and have the ability to perform the compliance activities successfully. This approach, in which there are goals and collaboration, must be considered in the context of the adolescent's cultural identity and developmental level. For all adolescents, but especially for those with chronic and stigmatized conditions, the desire to be normal is paramount. Normalcy is a social construct, communicated among peers, and it is also defined culturally (Taylor et al. 2008:3088), so it is important for the health care team to be aware of the cultural influences that guide their patients in integrating their disease management with the other facets of their lives.

Despite the thousands of studies of compliance (Trostle 2000) that have been published in the last several decades, complete adherence to medications remains difficult to attain (DiMatteo 2004), and difficult to measure (Simoni et al. 2003; Wiener et al. 2004). In addition, adherence itself is defined individually, and it is often conceived and assessed differently by the patient and by the practitioner. For the patient, as Trostle (2000) noted, taking medications is more than the instructions given by the doctor; taking pills has many meanings within the context of the adolescent's life, and these meanings determine how those pills are taken and how important the person considers his or her adherence. The discord brings up the definitions of adherence and compliance, and the loci of power and control that inhere in those definitions. Trostle (2000) and many others accept Haynes's definition of medical compliance as "the extent to which the patient's behavior...coincides with medical or health advice" (Haynes 1979, quoted in Trostle 2000:38). The word 'adherence' is often used in this definition, and the two terms are used interchangeably. Fawcett (1995; cited in Trostle 2000) made the distinction between the two words, suggesting that adherence is being faithful to the medication plan, whereas compliance evokes conforming to the practitioner's instructions. The distinction is trivial if one argues that the medication plan, after all, is given to the patient per the practitioner's instructions, and the authority in any case rests with the practitioner.

Trostle maintains that adherence is an ideology, and as such, judges the patient's adherence behavior "in terms of *imposed* professional expectations" (Trostle 2000:41; emphasis added). It is the power exercised in the practitioner-patient relationship, and the efforts, if any, that are made to establish trust and collaboration in this relationship that have implications for the way in which the patient accepts and acts upon the

information shared during the medical encounter. For adolescents attempting to establish autonomy in decision making, this power relationship may be especially precarious. They also may feel reticent about being truthful with providers because of the power the provider wields, not only to instruct but also to rebuke (Rao et al. 2007:32). Researchers have addressed this issue by looking at an empowerment-based approach to adherence (Aujoulat 2008; Veinot et al. 2006) and at the patient as partner in the provider-patient relationship (Thorne and Paterson 1998). Not only would a more collaborative medical encounter and ongoing relationship distribute power in a more meaningful way for the patient, but it would also provide the opportunity for the provider to learn about what medication means to the adolescent, beyond its “active ingredients” (Trostle 2000). With the ever-common problem of less than optimum adherence, the need to examine what disease, medication, adherence, and wellness mean in the everyday lived experience of perinatally-infected, HIV-positive adolescents is as great as ever. For this group of children on the brink of adulthood, which is an unexpected but current reality, this effort to understand and help improve their lives by making disease self-management something they believe they are capable of engaging in efficiently, is an obligation that cannot be delayed.

Disclosure of HIV Diagnosis

Parents, caretakers, and health care providers face the complex task of revealing to perinatally infected children the nature and name of their illness, and there is wide variation among these adults on when and how disclosure should occur. Before the era of HAART, children were not expected to survive beyond childhood or early adolescence, and so parents often could not (in the case of infants) or opted not to identify the disease

to their child (Domek 2006). Since combination antiretroviral therapy has improved both the quality and length of life, that option is no longer feasible, though many parents often delay disclosure for years (Abadia-Barrero and LaRusso 2006). The issues and attitudes involved in disclosure to a perinatally infected child are personal, social, emotional, and cultural, and will determine whether a parent or caretaker chooses to disclose in early or late childhood (Wiener et al. 2007:157).

Parents and other caretakers report reasons for and against disclosing to the HIV-infected child, particularly at a young age. Most commonly, they maintain that children are too young to understand the diagnosis, would share the information impulsively and inappropriately, might have negative emotional reactions, might experience psychosocial harm (depression, social stigma, etc.), and in the case of biological parents, would be angry with them (Vaz et al. 2010:248; Wiener et al. 2007:156). A small percentage in one study expressed the wish to protect the child's innocence (Wiener et al. 1996, cited in Waugh 2003:170). On the other hand, they have appreciated the importance of disclosure when adherence to medications becomes problematic, the child is approaching puberty and possible sexual activity, and in general because the child needs to know how to protect others from infection (Vaz et al. 2010:250; Wiener et al. 2007:156). The disclosure issue, however, not only addresses the child's readiness to accept the diagnosis, but is a function of the parent or caregiver's emotional readiness to impart this information and deal with the subsequent reactions and questions (Waugh 2003:170). In particular, children living with biological parents or related kin are known to be disclosed to less often than their counterparts living with unrelated caregivers (Ledlie 1999), the biological parents or relatives being reticent to address the parents' history of HIV

infection and their role and associated guilt in the child's infection (Ledlie 1999; Lipson 1993). Mothers also may not disclose for reasons of denial or possible negative reactions from partners and family (Mitchell et al. 2008:45).

The American Academy of Pediatrics recommends disclosure to school-age HIV-infected children in a manner that takes into account the individual child's cognitive development and social context (Wilfert et al. 1999). The practice of openness about illness in children with cancer became common in the 1970s, when survival rates increased and children's rights were being noted and discussed (Wiener et al. 2007:155-6). However, open communication may be more difficult with HIV than with cancer, due to the continuing stigma associated with HIV, maternal guilt, and the complicated issue of HIV as a disease of the family, all of which characterize HIV and differentiate it from other chronic childhood diseases (Lesch et al. 2007; Wiener et al. 2007; Cohen 1994). Studies have nonetheless shown that young children understand the concepts of illness and death (Bibace and Walsh 1980; Bluebond-Langner 1978; Lipson 1993), and are aware of their conditions even if parents are silent about them (Wiener et al. 2007). In addition to children's knowledge of and attention to what is happening to them, there is the possibility that children will overhear their diagnosis being named and discussed by medical providers (Instone 2000:242), and that it is better for them to learn their diagnosis through a deliberate process planned and undertaken by parents, caretakers, and medical providers (Lesch et al. 2007).

The psychosocial effects of disclosure to children are inconclusive across many studies and report a range of psychosocial and emotional effects (including a lack of effect [Instone 2000]) of disclosure and nondisclosure (Wiener et al. 2007), though a

longitudinal study of perinatally-infected children found no significant difference in the quality of life of these children before and after disclosure (Butler et al. 2009). Some children report that they felt sadness and worry upon hearing their diagnosis, and others responded with “a quiet acceptance” (Oberdorfer et al. 2006:285), but there were also positive aspects to disclosure (Vaz et al. 2010) and perhaps a greater willingness to make health care decisions (Lesch et al. 2007). Of special significance is the positive correlation between full disclosure of HIV status to children and adherence to medications (Bikaako-Kajura et al. 2006).

The prevalence of nondisclosure of HIV status to children is widespread, with similar outcomes from studies in Europe (Thorne et al. 2000), Brazil (Abadia-Barrero and LaRusso 2006), France (Funck-Brentano et al. 1997), India (Arun et al. 2009), South Africa (Kouyoumdjian et al. 2005), Thailand (Oberdorfer et al. 2006), and the United States (Flanagan-Klygis et al. 2002; Lester et al. 2002; see Wiener et al. 2007 for a review). While nondisclosure may be part of a cultural and social environment that dictates silence and secrecy (Hejoaka 2009), it serves to ensconce the child’s illness experience in “an embarrassing private world and becomes a shameful characteristic of the self” (Abadia-Barrero et al. 2006:40). The disclosure of HIV status, on the other hand, clarifies and legitimizes for the child the lifelong experience of seeing doctors, taking medicines, and being sick, thereby reducing anxiety and confusion and, over time, providing a sense of relief and normalcy (Abadia-Barrero et al. 2006:37). With disclosure of their disease, children were shown to understand their health condition better (Gerson et al. 2001), which could lead to the child’s exercising autonomy and more

successfully “attempting to achieve cognitive mastery over their bodies and lives” (Lipson 1993:8).

Disclosure is a complicated venture, embedded in the larger, ongoing family story of HIV, and many have suggested that it not be a discrete event but rather a process, an ongoing dialogue (Lipson 1993). The benefits of processual disclosure to school-age children convey the idea that it is not so much “*whether*, or even *when*, but *how* to speak with children about any disease” (Lipson 1993:8; emphasis in original). The content of the discussion must certainly coincide with the child’s cognitive ability, and involves more complex explanations as the child gets older. However, partial disclosure or false attribution of the child’s illness, which are very common among caregivers (Arun et al. 2009; Oberdorfer et al. 2006; Funck-Brentano et al. 1997) can violate trust, cause suspicion and anxiety when questions remain unanswered, and lead to rebellion through non-adherence (Bikaako-Kajura et al. 2006). On the other hand, children rated trust very highly as a reason for disclosure (DeMatteo et al. 2002).

Health care providers often favor disclosure earlier in the child’s life than parents or other caregivers deem appropriate (De Baets et al. 2008; Klitzman et al. 2008). Thus, the process of disclosure may clash with a family’s cultural perspectives and social standpoint, so health care providers need to be aware of the dilemmas which preclude disclosure that many of their families face (Lipson 1994). Despite the differences in when disclosure should occur, many caregivers voice their desire for support and input from providers during the disclosure process (Myer et al. 2006). The “developmental illness experience model” presented by Abadia-Barrero et al. (2006) and the characterization of disclosure as an “ongoing and dynamic” process (Ledlie 1999:148)

reflects the importance of recognizing the increasing maturity and cognitive development in children, the unique but changing sociocultural factors, family issues and caregiver needs, and the gradual nature of understanding what AIDS means to the child and the family (Abadia-Barrero 2006). The process approach to disclosure can also include the health care providers, who often have long, trusting relationships with perinatally infected children. The dialogue between caregivers and providers “may resolve the tension between caregivers’ and healthcare workers’...divergent understanding of disclosure and views of the child” (Lesch et al. 2007:815) and help them prepare for the ongoing dialogue that both the caregivers and the clinicians will have with the child.

In addition to the social, medical, and emotional reasons for disclosing the HIV diagnosis to children, there has been increasing attention given to the right of the child to know his or her diagnosis and thus begin to learn the personal and public health ramifications of successful HIV disease management (Wiener et al. 2007). The efforts to protect a child from the disturbing revelation of his or her incurable, stigmatized disease are counterbalanced by the ethical exigencies that take into account the child’s desire for answers and capabilities to exercise responsibility (Lipson 1993, 1994). Three broad ethical issues surrounding disclosure of an HIV diagnosis to children are the consensus on when to disclose, the competing rights of parents and children, and the health ramifications for both child and society (Klitzman et al. 2008). These complex issues entail conflicting opinions and rights – health care provider versus parent, parent versus child, and child versus society – which must be addressed on a case by case basis. Approaching disclosure as an ongoing process, with the collaboration of parents and health care providers, can provide needed time to address these issues and form a

consensus on what is best for the particular child and family. Blasini et al. (2004) developed a disclosure model comprised of pre-disclosure education sessions for providers, caregivers, and children, a disclosure event, and post-disclosure sessions. The model takes into account the different conceptualizations of disclosure by providers and parents, and encouraged partnerships among all parties (Blasini et al. 2004:183).

Anthropology and Childhood Studies

Children and childhood have been studied by anthropologists since the discipline's beginnings in the late 19th and early 20th centuries. Books and monographs contain details of the place of children in kinship relations, child rearing and socialization practices, and initiation rituals, among other topics. (LeVine 2007). The focus on children, as social actors, with their own points of view, did not, however, begin to develop until the 1920s and 1930s. Margaret Mead, well known to scholarly and popular audiences, conducted research with children and adolescents (Mead 1928, Mead 1932; Bateson and Mead 1942), in which she looked at children's thought, adolescent development, and interpersonal relationships. One of the stumbling blocks in the early anthropological studies of children as learners of culture was the dependence on psychology for developmental theories of the child, which as LeVine notes, were "unreliable, as one developmental theory followed another into the trash heap of history" (LeVine 2007:249). In addition to the loss of credibility, a difficulty with many psychological theories was that they did not acknowledge cultural differences and influences, but rather considered stages of cognitive development, moral development, and attachment, for example, to be universal (LeVine 2007:250). Toren goes further still

in implicating “the notion of the child as an a-social, a-historical individual...in the various psychological and anthropological theories of cognition” (Toren 1993:471).

Subsequent anthropological research saw the move away from dependence on psychological theories of stages of development and cognitive structures, though Hardman acknowledged the benefit of including a “formal list of analytical notions” (Hardman 1973:516) qua Piaget and Levi-Strauss. Then in the 1950s and 1960s, John and Beatrice Whiting and colleagues developed and carried out comparative ethnographies known as the Six Cultures Study (Whiting 1963; Whiting and Whiting 1975), which was “systematic naturalistic observation of children...in their routine ‘behavior settings’” (LeVine 2007:253). The importance and value of studying children in their own right gained some traction from the 1960s onward; nonetheless, Hardman, in 1973, was asking “Can there be an anthropology of childhood?” and proposing the exploration of children’s worlds as more than just training for adulthood (Hardman 1973:501).

The 1980s and 1990s saw this shift in the study of children and childhood to an even greater emphasis on the children as autonomous beings, not just “adults in the making” (Brannen 1996:114). The 1989 United Nations Convention on the Rights of the Child (UNCRC) underscored the stature and separateness of the child, and his or her human rights and needs for protection (United Nations 1989). The recognition of the child as creative cultural actor as well as the influence of environmental variation on childhood together moved anthropology into a new paradigm of childhood studies that saw its genesis in the 1980s (James 2007).

General Conceptualizations

Children may have been regarded as just part of a larger kinship group, or a stage on the way to adulthood, but what anthropologists did recognize through ethnographic study was that sociocultural norms were dependent on environment and that childhood environments exhibited wide cultural variation (LeVine 2007:248). The new childhood studies of more recent decades have focused on the child's environment as a culture separate from the dominant adult culture and the child as an autonomous social actor. This called into question the idea of childhood as a liminal stage (James et al. 1998:198) and young children as precultural or presociological (James et al. 1998). The idea of children "as empty buckets filling up with culture" was thus rejected, and participation of children in research was emphasized, so that data was gleaned from children themselves (Benthall 1992:1). The acknowledgement of children's contributions led not only to a new anthropology of children, but also to a more comprehensive anthropological lens on culture (Bluebond-Langner and Korbin 2007:242).

This bold turn in childhood studies meant that children were approached as independent members of culture and society, with their own subculture and capacity to formulate meanings during their interactions within this subculture (Bluebond-Langner and Korbin 2007). Toren (1993) argues that children's acts and ideas, and the meanings they construct, are socially mediated, historically situated, and based in experience, and are distinct from, and can even be oppositional to, the meanings of adults. In order to examine the context and experience of children as they not only acquire but also create, transform, and challenge culture (Kyratzis 2004; Toren 1993), their voice and status are highlighted (James 2007; James et al. 1998). The currency of the notion of children as

articulate talkers and formulators of meaning is demonstrated in studies and theoretical discussions, such as talk and social competence (Hutchby 2005), talk and peer culture (Kyratzis 2004), adolescent talk (Baker 1984), and the importance of listening to children's voices in research (Roberts 2000). The status of children refers to their present selves, as opposed to their slowly but continuously developing selves growing toward adulthood. This duality in childhood – being and becoming – is discussed further below.

The emic perspective of children in anthropological and other social science research aims to counter the longstanding powerlessness and silence of children in social life. By designing research in which children can be heard, their voices not being “silenced, suppressed, or ignored” (James 2007:261), the study of culture and social organization can be enriched by the information gained from the standpoint of the child (James et al. 1998:31). At the same time, the child's perspective fosters social understanding, recognizes the child's right to expression, and can serve as a basis for policy. (McKechnie and Hobbs 2004). However, this approach to a socially active childhood and to the child's standpoint, which James et al. (1998) define in four sociological types of varying autonomy and power ascribed to children, raises the prospect of overgeneralization by glossing over the individual and cultural diversity among children and childhoods (James et al. 1998:30-1; James 2007). This homogenization of childhood can be prevented by the participation of children as co-researchers and with particular anthropological methods of inquiry. These are discussed in Chapter 3, as will the use of children's voices and the issue of representation (James 2007). In addition, the medical ecology framework can mitigate such false homogeneity

as it places children in particular contexts and highlights specific social interactions within those contexts. This framework is discussed below.

While one of the foundations and aims of the anthropology of childhood is to dispel the notion of the immature child (Toren 1993), and to demonstrate the competence of the child as social actor and culture creator, it is important to recognize that childhood is fluid (James et al. 1998:203-4), children change rapidly, and their lived experience occurs within and is affected by a social structure that includes adults and adults' influences. With regard to children's experience of illness, the notion of fluidity extends to the child's wellbeing (Crivello et al. 2009), and therefore, his or her management of disease may likewise be fluid. The duality of being a child in time and place and becoming older as one moves toward adulthood is addressed by scholars of childhood studies, who attempt to contrast, rank, balance, and assimilate them. Uprichard insists on assimilation, that "children and childhood are *always and necessarily* 'being and becoming'" (Uprichard 2008:303; emphasis in original). She notes that children themselves are aware of both statuses and she argues that each shapes the other (Uprichard 2008).

Despite Uprichard's concern that in focusing on the being child, the "temporality of the 'becoming' child has...been lost" (Uprichard 2008: 306), anthropologists and other social scientists have maintained this focus as a counterpoint and corrective to past structures and conceptions that presented the child as objects rather than subjects (Christensen and James 2000), natural as opposed to cultural (Jenks 1996; LeVine 1998; Panter-Brick 1998), incompetent (James et al. 1998), and waiting (Qvortrup 2004).

Childhood Studies and Management of Chronic Stigmatized Disease

The idea of being and becoming in childhood raises two issues which are germane to the study of adolescents' management of perinatally-acquired HIV: the agency-vulnerability dichotomy and temporality. The new childhood studies, including the anthropology of childhood, reject a hard structural determinism and mere social reproduction in children, and instead emphasize the child as a competent social actor capable of producing a separate childhood culture (Jenks 1996; James et al. 1998) as well as interacting with adult culture and, in so doing, transforming, challenging, and learning from it. James and James present a model, based on Mary Douglas's grid-group matrix of social organization (Douglas 1973, cited in James and James 2004:53), whereby the production and reproduction of childhood occur in time and space. It comprises Law, which they define as normative, mediative, culturally-reflective

processes and mechanisms of regulation that exist in all societies, both religious and secular...comprising a system of principles and practices that underpin the social construction of a wide range of behaviours, attitudes, beliefs and relationships...[and] defines the rights and responsibilities of, and therefore the relationships between, citizens in any given cultural and political context. (James and James 2004:49)

The Law is situated between, as it were, the social space that is structure, and social action, which is agency, and mediates the process by which structure and agency affect and are affected by the other (James and James 2004:57). The model allows for variations in children as actors, both as particular members of particular societies and as members of a human group with certain similarities, and for the existence of plural childhoods as structures, similarly ranging from the particular to the general (James and James 2004:58-60).

The growing prominence of childhood and children as distinct entities in particular societies (and at the level of more global structures, e.g., the UNCRC) at this particular moment is evident in the more visible and influential roles of children, and reflects changes in the social order and cultural practices (McKechnie and Hobbs 2004). The UNCRC (1989) is one such action. In all societies, the cultural, economic, political and social contexts provide the particular nexus for responses about, toward, for, and by children. The social changes and the social continuities, in addition to the regulations which mediate the social order, are controlled by adults (James and James 2004:25), so the agency of children necessarily involves the interaction between adults and children, and the uneven power relations between them. For example, the power of adults is questioned by Woodhead (1990) in his rejection of the characterization of children's needs as straightforward observable facts by authoritative adults. This way of looking at needs dismisses the particularities and competencies of children. It is within these adult-child relationships that the child's vulnerability appears in a paradoxical coexistence with agency. This mix is perhaps more dialectical in nature than paradoxical, as the child's agency is a reaction *and* a response to vulnerability that accompanies a particular stage of childhood. Aside from the most common areas of interaction, the family and the school, the health care system serves as a setting for adult-child connection and communication, and the sick child is one example of the coexistence of agency and vulnerability.

Perinatally-infected children's vulnerability stems from their status as children, their sick role, and their compliance with the adult professional medical sphere. It is this idea of compliance, as a judgment of a patient's behavior with regard to professional expectations, which keeps authority safely within the hegemonic walls of medicine and

the adult world (Trostle 2000). Thus, the perspective of the HIV-positive adolescent, as well as his or her individually-shaped management, can demonstrate the active role and precise meanings that adolescents develop in response to their illness. The health care provider's understanding of the patient's perspective is a necessary step in the forging of a partnership in health care treatment that spreads rights, responsibilities, and power among the participants and may ostensibly lead to better management and better health. This recognition of agency in health management helps to reduce the adolescent's vulnerability.

The concepts of being and becoming in childhood raise two additional issues that are relevant to the lives and disease management of HIV-infected adolescents, particularly those infected at birth. These are temporality and embodiment, which are experienced uniquely by children and in childhoods, and must be examined by looking at the child or adolescent's autonomous culture (Crivello et al. 2009; Hirschfeld 2002:613). Both are sociocultural constructions as well as physical realities, and are experienced by adolescents and children in ways that are distinct from adult conceptions and experiences. For the chronically ill child or adolescent, there may be developmental and psychosocial effects that stem from the constant presence of illness. For the HIV-infected child in particular, the disease may result in reduced height and weight, as well as delayed pubertal development (Buchacz et al. 2003), which can alter both temporal and embodied experience. The fact that HIV and other diseases, disorders, and disabilities are physical conditions has often obscured the social and cultural meanings and the different ways that they can be experienced, and the different cultures that children, including ill children, construct apart from adult culture (Hardman 1973). In Davis et al.'s approach to children

with disabilities, “overcoming the unitary notion of the disabled child” (Davis et al. 2000:206) permits the revealing of structure-agency interactions and changes that children effect in their particular environment (Davis et al. 2000). Time and embodiment, and their meanings, are two such phenomena that children with HIV are shaped by and which they in turn reshape as they experience life with HIV.

The importance of time in childhood is revealed in expressed attention to age, constructions of age grades and age classes cross-culturally, and its future orientation (James and Prout 1990). In addition, the passage of time during childhood shows evidence of ongoing developmental changes, and the social meanings of these changes, as well, shift over time (Toren 1993:462) and across cultures (Hockey and James 2003: 4-5). The process of ageing and the passage of time are thus “qualitatively” experienced, and childhood “is less a fact of nature and more an interpretation of it” (James et al. 1998:62). Ethnography has revealed very different experiences of ageing, where, for example, the demarcation of childhood/adulthood is made by parenthood or betrothal rather than by chronological age (James et al. 1998:63). Rites of passage and initiation rituals are also social and cultural acts that symbolically indicate the end of childhood and the entry into adulthood, a process of ageing and change that are not necessarily evident without the rituals (Hockey and James 2003:46-7).

The future orientation of time in childhood may be especially problematic for adolescents with perinatal HIV. Many of these young people were not expected to have a future, so they may not have a strong sense of “becoming” adults. They may not see how their past and present relate to their future (Uprichard 2008), or they may see who they are as what they may never become. The generational relationships, which differentiate

children from adults (James et al. 1998:66), must also be explored, for the fractures in these age links through untimely death may also affect the adolescent's sense of time. How these adolescents construct and attach meaning to their pasts and presents, and those of their parents, becomes salient when we explore their attitudes toward medication adherence. Adherence to antiretroviral therapy is the only means of giving HIV-positive individuals the opportunity at a future, but these children, who have been ill all of their lives but now know their diagnosis, may not envision a future at all. Thus, adherence may seem nonsensical, and their present needs may be all that concern them. On the other hand, some of these adolescents may see medication as their last-ditch effort at a possible future, and therefore practice adherence faithfully. The meaning of time and ageing, and their conceptualizations of the future may also have implications for their emergent sexuality; the effects of risky sexual behavior, for them and for their partners, are in the future, and this may or may not have meaning for them. Whether or not they engage in risky sexual behavior, adolescents are developing a sexual identity and perspective on sex, and making decisions based on these developments (James and James 2004:155), so it is essential to know their perspectives and the elements that constitute their adolescent culture in order to address their health-related implications. The chronicity (from birth, in this case), gravity, and stigma of HIV, therefore, necessitate an examination of perinatally-infected adolescents' perspectives on time, in the culture that they create in the present, which may be very different because of their experience living with HIV.

Health care providers have a key role in the lives of perinatally infected youth. They have been involved in some of their patients' lives continually since birth. As

medical care providers, they necessarily see the patient's future as a priority in their decisions about care and treatment, and thus the child's everyday experience are considered, if at all, only for their future consequences (James et al. 1998:74). The disagreement between provider and patient, and the noncompliance of the patient may be the consequence of the routine view that children are incompetent and of value as "potential" adults rather than of interest as actual children. The success of medicine often risks seeing patients' success in terms of survival, that is, the future, rather than quality of life, that is, the present. The structure of time and the interpretation of the future also figure into adolescents' transition from pediatric to adult health care (Pontali 2005). Pediatric HIV health practitioners in FAN acknowledge the difficulty of this change in their patients' lives, and their understanding of the temporal currents of these lives and of how these patients view this transition may facilitate a process by which the integration into adult care is made.

As we have seen, the theoretical basis of the new childhood studies is the child as competent social actor, meaning maker, and cultural author, viewed from the perspective of the emic present where agency and structure are balanced (Prout 2000:3). This design is underpinned by a social constructionism and, as will be argued below, by the medical ecology in which the perinatally-infected adolescents are situated. It also argues against a strict biological determinism and structuralism that sees children as prisoners of their physical and psychological stage in life, developing gradually until the attainment of the freedom of adulthood. That said, children, like the rest of us, are embodied beings, and while it is the theoretical view presented here that social and cultural variations fashion a heterogeneity of children and childhoods (and vice versa), one must recognize that the

lived experience of all young people is an embodied experience, and the experience of the body has effects on the person's lived experience. In addition, illness, health, and disease are physically as well as socially experienced phenomena. Thus, the exploration of adolescents' meanings and management of HIV may benefit from an exploration of how the "body (and its processes of change) forms an entity that is experienced and...interpreted by different actors in different social and cultural contexts" (Prout 2000:3-4). The notion of the chronically and seriously ill child summons up vulnerability, to which many in the new childhood studies object, at least as a wholly biologically determined state. Rather, as Christensen argues, vulnerability is a culturally and socially constructed status which, particularly in childhood illness, consigns the child to dependence upon adult caregivers and ignores his or his knowledge and experience of illness (Christensen 2000:38). Bluebond-Langner demonstrates quite convincingly in her poignant study of terminally ill children that they are very aware of what is happening to them, and very knowledgeable about their illness and its treatment (Bluebond-Langner 1978).

For the HIV-positive adolescent, physical and physiological changes in the body, opportunistic infections, and medication side effects are all part of the illness experience. The benefits and drawbacks of antiretroviral therapy are part of the fluidity of wellbeing, and their impact on the youth's social and embodied identity may in turn affect their decision making with regard to adherence and other disease management activities. The vulnerability and incompetence, along with the associated dependence that adults, including health care practitioners, often attribute to young people are constructions of childhood that lead adults to interact with children authoritatively and protectively,

effectively blocking the centrality and visibility of children's agency with regard to their bodies (Prout 2000) and interfering with or complicating their disease management.

The contradictory discourse of the child (Brannen 1996:115) as, on the one hand, a dependent and incompetent individual whose agency is ignored and, on the other hand, a child who is expected and encouraged to comply with medical instructions, points to the need for approaching the child, and especially the adolescent, as a more active participant or partner in the undertaking of tasks and construction of meaning normally thought of as resting in the adult domain. The puzzlement of the stage and status of adolescents with HIV, and perhaps especially those with perinatally acquired HIV, raises the issues of transitionality and liminality that define these young people. Adolescence can be seen as a liminal space where the individual is no longer a child but not yet an adult. Rites of passage in many cultures mark this transition (Hockey and James 2003). The sick person, and in particular, one with a chronic illness, may also be liminally identified, for the Parsonian sick role, with its limits and roles in the sickness stage and the recovered health stage, is not complete (Crossley 1998:508). The chronically ill, while never relinquishing their illness, nonetheless can spend extended periods of time in good health and are expected to fulfill responsibilities associated with good health (Crossley 1998:508). For perinatally infected adolescents, the period of liminality may include an acute phase, in which the person is overwhelmed by the diagnosis of HIV, and an enduring phase, which sees the person as perhaps healthy but always HIV-positive (Little et al. 1998) Therefore, the experience of HIV may be a source of confusion for the young people and for those around them. It may, however, also be a conceptual time and

space where their competence as social actors and creativity in culture making is evident, as they occupy this way of being uniquely.

This liminality may extend to the context of the health care system and provider-patient encounter, where the representations of the sick child remove the child in his or her socially and physically lived experience and replace him or her with “‘technodressing’ [or] the generation of mathematical symbols which represent the corporeal body” (Place 2000:176). The HIV-infected adolescent or child becomes his or her viral load and CD4 count; his or her life outside of the clinic is the number of medications and their schedule and dosage.

Research Ethics: Ethics and Research with Children

Research with children and adolescents is considered ethically challenging because of their characterization as vulnerable. Children possess less cognitive ability, less lived experience, and less power vis-à-vis adults. Their need for protection in a variety of situations is recorded in the United Nations Conventions on the Rights of the Child (1989). Their rights are duly noted in this document as well. The involvement of children in research requires a search for balance between these needs and rights. The theoretical perspective that guides the anthropology of children characterizes children as agentive, competent, social actors, whose participation in and contribution to cultural systems is important and necessary to study. Yet, historically, the researcher has been in control of the research design, methodology, direction, and analysis, so that the power and contribution of children (and indeed adults) to the process and outcomes of research can be and are perceived to be inferior or minimal compared to that of the researcher.

In order to approach research in an ethical manner, in which the interests of the participants are discerned and legitimated, evaluated and addressed, it is incumbent upon the researcher to examine the issues that make research with young people problematic and, in the course of addressing these issues, make informed decisions about the research methods that best elicit findings that are acceptable and beneficial to all involved (Whiteford and Trotter 2008).

Research with human subjects has a checkered history. While remarkable breakthroughs in medicine have occurred as a result of such research, it has also been the source of horrifying, harmful, and, to those involved, unknown consequences. In order to protect participants, define responsibilities, rectify the ills of the past, and safeguard and guide all who are involved in research with human subjects, a number of reports, strategies, principles, and treatises have been created and introduced to the public and to researchers, in the United States and internationally.

The Nuremberg Code of 1947 resulted from the record of atrocities in World War II, in which people were forced into experiments, and the Nuremberg Trials which took place after the war (OHSR 1949). The Code's principles include securing the research participant's informed consent to take part in the research and the right of the participant to end his or her participation at any time. The World Medical Association adopted the Helsinki Declaration in 1964 (WMA 2008). This is a policy statement that delineates protections of participants in medical research, and addresses the issues of gaining assent from those deemed incompetent, presumably including minors (WMA 2008).

Despite the establishment of the 1947 Nuremberg and 1964 Helsinki ethical codes, and other international documents, exploitative and harmful research continued.

In the United States, the Willowbrook State Hospital (1956-70), Jewish Chronic Disease Hospital (1963), and Tuskegee Syphilis (1932-1972) studies are three examples (UNH n.d.) of research that was conducted on both children and adults without their knowledge. In 1974, Congress passed the National Research Act, which provided for the creation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The commission was charged with identifying ethical principles to guide federally-funded research; this was published as the Belmont Report in 1979 (OHSR 1979). This report explains three basic ethical principles – respect for persons, beneficence, and justice – that are considered imperative in research with human subjects, as well as the applications of these principles in the carrying out of research.

The applications of the principles of ethical behavior in research, while relevant to adults and children alike, highlight some of the issues of vulnerability and protection in research with children. They include informed consent, information, comprehension, privacy, and voluntariness, which acknowledge the principle of respect and autonomy; assessment of risks and benefits, and the nature and scope of risks and benefits, which apply the beneficence principle; and the selection of subjects, which applies justice (OHSR 1979).

Age is one aspect of a person that determines vulnerability, and it is accepted in many, if not most, cultures that the young are a vulnerable group (Whiteford and Trotter 2009:88). While the ethical guidelines of the American Anthropological Association and the Society for Applied Anthropology do not specifically mention children as a group, the British Sociological Association contains the phrase, “Special care should be taken where research participants are particularly vulnerable by virtue of factors such as age, social

status and powerlessness,” but it does not provide details of ‘special care’ (quoted in Morrow and Richards 1996:93). Children are generally vulnerable on all three counts, and for children with a serious disease or disability, there may be additional factors contributing to the possibility of harm or exploitation.

The theoretical perspective that will guide my research sees children and adolescents as competent social actors, capable of agency in their own social, cultural, and medical settings (James et al. 1998). Their lived experience in their particular environment is the basis for understanding how they manage their HIV disease, including medication adherence. This perspective recognizes that power lies with the adolescents, both in their lives and in their participation in the research. The acknowledgement of power in a group which is generally perceived and treated as powerless adds ethical and methodological “complexities and uncertainties to the research process by interposing a new actor and thus a new set of social relations into the field” (Christensen and Prout 2002:482). The complexities may be addressed by treating the ethical concerns as an ongoing process, to be revisited throughout the research study (Helseth and Slettebø 2004), and by carefully choosing methods that best allow both a smooth process and forthright content as a result of the adolescents’ participation.

The starting point for addressing the ethical issues in research with perinatally-infected adolescents with HIV/AIDS is thus the same as it would be for research with adults. The participants must be fully informed of the research and of what their participation will entail, their understanding must be established, and their informed consent to participate must be freely given. For those who are not at the age of consent, assent must be obtained, which is taken to be “affirmative agreement” and not just

“failure to object” (DHHS 2005), and informed consent given by parents or other responsible caregivers. The youth must also be made aware of their right to withdraw from the study at any time and their prerogative to refuse to engage in any part of the research. These are all aspects of the principle of respect for persons, and includes respecting the participant’s autonomy. An important theoretical basis of this study is the standpoint of the child or adolescent as an autonomous, meaning-making individual, yet one with certain vulnerabilities (Balén et al. 2006:44). This somewhat ambiguous standpoint of children in research necessitates that their voices be heard (Balén et al. 2006:44). The protection of vulnerable populations during the research process may be achieved through a partnering relationship in which children can be heard during each phase of the research and thus have ownership of the data (MacNaughton and Smith 2005:116). Making judgments of each adolescent’s competencies, willingness, and comfort may be more easily discerned through the forging of these relationships. In addition, the choice of methods will also reflect the attention that is given to protecting the young people.

The second ethical principle, beneficence, requires that research confer benefits, and is sometimes paired with the avoidance of maleficence or the causing of harm. This is intended to guide research design, data collection, and presentation of findings in ways that will benefit participants or others in society while doing no harm. The benefits to participants are linked to the third principle, justice, by tapping children and adolescents for research in the first place. In attempting to protect them because of the traits that render them vulnerable (age, inexperience, powerlessness), children have often been excluded from studies in which their presence and participation would provide key

insights and results that only their perspective can reveal. For the adolescents living with perinatally acquired HIV, parents, caregivers, medical providers, and other adults can provide information that is significant, but they cannot tell us what it is like to be fifteen and HIV-positive. The invitation to participate in research about *their own* disease management is a sign of respect, an opportunity for beneficence, and indeed an act of justice that need not be missed if the young people are approached and included from the perspective that they know, they analyze, they devise, they create, and they manage, and they can convey their experiences competently and cogently. The seriousness and urgency of optimum medication adherence, in terms of managing HIV in the present and for the future of these adolescents and others around the world, demand that they be included in research, for their perceptions will contribute to filling in the gaps that currently exist in improving adherence (Mullender et al. 2002: cited in Balen et al. 2006:31). The findings and subsequent interventions may be felt by the participants themselves, may have ramifications for children born with HIV elsewhere, and may indeed be a matter of life or death.

As with any research with human subjects, particularly qualitative research, the problems for participants and ethical dilemmas for the researcher cannot be totally anticipated and avoided at the outset (Murphy and Dingwall 2007), and in research that involves the lived experience of a serious, chronic, stigmatized disease like HIV, the potential for distress certainly exists. One must be aware and prepared for the situations in which the effects of an interview or other exercise are negative (Nicolas and Schilder 1997:88). The Florida Family AIDS Network is a multi-agency, comprehensive system of care, and the availability of social workers, mental health professionals, and other

clinical personnel is built into and supported by the network, and provided a safety net for the young people who might have needed or wanted counseling during the research project.

Medical Ecology

The research on children with HIV and their adjustment to and management of HIV disease is varied in its findings. Some studies show children with HIV having greater psychosocial problems than healthy counterparts, while others do not show any variation (Steele et al. 2007). Adherence issues may be successfully addressed by some adolescents and consistently problematic for others. The wide variation in findings on HIV in children and adolescents seems to point to the variability in children's social, cultural, and medical environments, that is, the social organization and Law (mentioned above) that "underpin behaviours,...rights and responsibilities" (James and James 2004:49). This supports the necessity of studying perinatal HIV and disease management among adolescents from a medical ecological perspective (McElroy and Townsend 2009; Panter-Brick 1998; Steele et al. 2007). The experiences of the adolescent, as they occur in and are part of his or her social and cultural environment, can highlight the heterogeneity of these experiences and responses to illness (Hunt and Arar 2001). This framework places the HIV-positive adolescent at the center of proximal and more distal contexts that interact with each other and variously influence the child (Steele et al. 2007). The proximal niche has direct effects on the child's agency, meaning making, and behaviors.

Two of the more proximal niches in which the adolescent is significantly engaged are the family and the peer group. In following the theoretical perspective outlined above

in the anthropology of childhood and the multidisciplinary childhood studies, the child is placed center stage as an agentive social actor. The interactions of the child and his or her family members represent one stratum in which the medical, environmental, and social influences on the child can be interpreted, keeping in mind that the family is part of the larger community and economic and political systems (Novilla et al. 2006). The family is the locus of activities and beliefs related to health, including food and nutrition habits, smoking and alcohol use, and physical exercise, in addition to the social factors like parent-child relationships, parental controls and protection, and educational and other forms of support and encouragement (Christensen 2004). The family setting as the most immediate environment for the child may also extend to the HIV care provider for the HIV-positive child, since this person or team is often a continuous and regular presence in the child's life (Ledlie 2001; Merzel et al. 2008). The family and health care providers have initial and significant influences on the child's own health practices and his or her attitudes toward illness and illness management.

The child's development within the family is examined through the family's activities rather than by the family structure, according to the ecocultural perspective (Weisner 2002). This perspective, which focuses on the family's "local situation," displays the routines and problems that are part of everyday life, and the specific cultural tools that they have at their disposal to deal with the particular environment in which they live and act (Weisner 2002). The focus on activities and family dynamics allows for the position of the child as social actor to be highlighted, as the family's health-seeking attitudes and practices shape the developing child (Christensen 2004). The family of the perinatally-infected child is a unique configuration, because the mother is necessarily also

HIV-infected, and other family members may be comprised of infected and uninfected siblings and father. In addition, the family may have experienced the deaths of family members, and the infected adolescent's caregivers may be extended family members (often a grandmother), foster parents, or other unrelated persons (Cohen 1994). Health as a resource and as a practice may be more or less restricted by the presence of HIV and its requirements, and the family dynamic and composition will affect the infected adolescent's wellbeing and experience of HIV disease (Steele et al. 2007). Some families may integrate health-promoting behaviors and attitudes more successfully than others, and it is the matrix of personal coping, supportive relationships, competing goals, and external mechanisms that determine how a particular family manages health needs and indeed how a chronically ill adolescent learns and exercises his or her own health-promoting behaviors (Christensen 2004).

A second niche in which the child acts as social and cultural member and which is part of the medical ecological space which he or she inhabits is the peer group. The dynamics of the HIV-infected adolescent and his or her peer group include the sharing and creation of unique cultural spaces and health practices that affect both the positive adolescent and his or her peers. Adolescents with perinatally-acquired HIV will manage their disease according to the allowances and constraints imposed by their own and their peers' schedules, attitudes, and understandings. They will also practice safe or risky sex based not only on knowledge and the influences of family and health care providers, but also on the peer culture and relationships in which such activities take place (Battles and Wiener 2002; Dodds et al. 2003; Kyratzis 2004).

The peer group as cultural space is characterized by children of similar age, and peer relationships are largely forged within the context of school. James et al. submit that children's culture is distinct from adult culture, and "emerges in and through the temporal, as well as spatial, interstices of adult social structures," but this culture is constrained, too, by temporal and spatial structures of children's own lives (James et al. 1998:75). They cite in some detail Amit-Talai's (1995) work with North American teenagers, which argues that young people have limited time in which to develop long and trusting friendships, and when child and adolescent peer groups are arranged by school grade and are thus similar in age, friendships with older or younger individuals are nearly impossible (Amit-Talai 1995; cited in James et al. 1998:76). The age-similar peer groups are very different from relationships that form in societies where schooling is or was not a social institution, and where children could therefore have contact with and learn from people of differing ages and experiences (LeVine 1998). Children in American society create cultures and contribute to social and cultural change, but this distinctive peer culture may be problematic in the kinds of knowledge transmission and social and personal growth that can occur. For the child or adolescent with a chronic, stigmatized condition like HIV disease, the constraints on the development of peer relationships are likely to be greater, because of the time and effort that must be devoted to illness management and the developmental delays and psychosocial challenges that may be present as a result of both medical and social (family) influences (New et al. 2007). These factors, in peer culture generally and in the peer relationships of the perinatally infected adolescent, demonstrate a complexity in childhood culture and in the navigation of childhood's temporal and spatial labyrinth, and are implicated in the way

that HIV-positive adolescents conflate their illness identity and responsibilities with their social identities and interactions.

The medical ecology perspective demands examination of environmental influences beyond the family and peer group. The child is at the center of an environment composed of immediate contacts, situated in the larger sociocultural community, all of which are influenced by macro-level social, economic, political, and ideological pressures (Steele et al. 2007). Though the child is a social actor in this environment, he or she is also an embodied individual who acts and reacts to biological forces in the physical environment. Part of the HIV-infected individual's medical ecological reality involves his or her infectiousness, the effect of medication adherence on the degree of infectiousness, his or her own susceptibility to opportunistic infections and to reinfection with a different strain of HIV, and the effects of medication on the person's physical wellbeing and ability to function normally in everyday endeavors (McElroy and Townsend 2009; Armelagos et al. 1990). The human immunodeficiency virus is very responsive to antiretroviral therapy, becoming suppressed within weeks of therapy onset, and multiplying at the first sign of suboptimum therapy adherence (Williams et al. 2006:e1753), yet there is not a one-to-one correlation between adherence and health measures (Steele and Grauer 2003:25). It also mutates and becomes resistant to medications in response to adherence levels. The personal, social, and cultural resources and stresses that are part of the adolescents' lived experience affect their ability to confront and cope with these aspects of HIV and determine how they manage their disease, maintain their health, and safeguards others, especially sexual partners.

Resistant HIV, which can be the result of medication non-adherence, can be transmitted to sexual partners, so knowledge of resistance and the importance of maintaining adherence to stave off resistance and maintain low viremia is an important part of the infected adolescent's disease management (Quinn et al. 2000). The social and biological aspects of successful HIV disease management have implications for public health and the increase or reduction of HIV transmission.

The medical ecology of HIV disease management places the HIV-infected adolescent in an actor-oriented position (Armelagos et al. 1990), encompassing the child as social actor espoused by anthropologists and other social scientists of childhood studies. In a medical ecological context,

health and disease [are situated] in a system of mutually interacting organic, inorganic, and cultural environments...[and] are informed by the perceptions and social relations of patient, healer, family, and community. Insults can originate from organic, inorganic, and all aspects of the cultural environment, and host response to insults entails modification or use of resources within all of these environmental subsystems. (Armelagos et al. 1990:358)

The perinatally-infected adolescent with HIV, having lived with the virus since birth, has had some experience coping with the disease and its sequelae. However, the individual, the disease, the virus, and the social and physical environments are capricious, and necessitate adaptive strategies as changes anywhere in the individual's environment occur. Adherence to medications is one such strategy and, in the case of HIV/AIDS, is currently the most effective medical strategy once a person has been infected. In looking at the wider AIDS epidemic, behavioral changes are an adaptive strategy aimed at preventing infection (Armelagos et al. 1990).

While medication adherence is the most effective health-promoting behavior for the HIV-infected individual, there are other adaptive behaviors that can facilitate successful adherence. These are located in the micro-, meso- and macro-systems concentrically circling the adolescent (Steele et al. 2007), in which people, community situations, and societal economics, politics, and ideology interact and influence the individual in his thinking and agency. If the resources are available at these various levels of influence to enable an individual to adopt health-promoting behaviors and attitudes, then he or she will thrive in the face of the medical and social obstacles presented by life with HIV (McElroy and Townsend 2009:306). The proximal levels of family, health care system, and peer groups have been discussed elsewhere. At the more distal levels, health care accessibility, health policy, economic conditions, and social attitudes toward illness are some of the features which influence the actions and interactions of the individual and his or her family, social, and medical networks (Pontali 2005; Steele et al. 2007).

In the medical ecology of HIV disease management, the cultural system is perhaps the key system affecting perinatally infected adolescents (Armelagos et al. 1990). From a clinical and logistical perspective, the young people who are receiving care as clients in the Florida Family AIDS Network are provided with the resources to maintain their health and minimize some of the previously common adverse effects of the medications and of the virus. However, the cultural system situates their embodied experience within their social relationships through the beliefs and other types of information that guide them to manage their HIV disease. Cultural beliefs may facilitate or thwart the adolescents' efforts at successful disease management and subsequent

health outcomes. For example, culture dictates secrecy in some families, yet disclosure to peers has been correlated with increased CD4 counts in HIV-infected individuals (Sherman et al. 2000). There are family complexities and economic difficulties that may impede regular clinic appointments and secondary health-promoting behaviors such as good nutrition. Whether adolescents are resilient in the face of the insult of HIV depends in great part on their cultural resources – their beliefs about self, their social support, the importance of and dedication of resources to health that they, their families, and communities (and society) defend – for “it is within culture that much of the behavior surrounding health and disease is played out” (Armelagos et al. 1990:358). Medical ecology brings together the physical and biological, the social, and the cultural effects of HIV, which merge in and around the infected adolescents to determine whether and how well they adhere to their medications, manage their disease, and reach an optimum level of psychosocial wellbeing and physical health.

Health is a multidimensional phenomenon (Novilla et al. 2006:38), and must be understood in its temporal and spatial situatedness. While obstacles to successful disease management exist which are beyond the individual’s control, in the proximal but especially in the political economic sphere, the possibilities for essential social change also exist in collective action (Armelagos et al. 1990:358) that extends beyond and into the various social settings of the ecological environment. However, at the center of the overlapping systems and ideologies that comprise this medical ecological environment are the perinatally-infected adolescents with HIV disease, who “actively constitute a world that is at once the same as, *and different from*, the world their elders know” (Toren 1993:463; emphasis in original). Their goals, resources, capacities, conceptualizations,

and experiences are at the heart of the study of adolescent adherence and disease management, and as the study of the aids and barriers to optimum disease management is pursued, taking into account the myriad ecological factors influencing the lives of these young people, it is mandatory to approach these persons as partners in the research, recognizing their power and control both in their lives (Armelagos et al. 1990:358) and in the research process. The theoretical perspective adopted by the anthropology of childhood and social scientific childhood studies, placed within a medical ecological framework, makes this possible.

CHAPTER 3: METHODOLOGY AND RESEARCH ETHICS

The methods used in qualitative research are many, and it is critical to choose methods that facilitate the collection of data needed to answer the specified research questions. Since children and adolescents are viewed as competent social actors, and are situated in distinctive environments where their personal stories unfold, individual interviews will allow the individual voices of the participants to be heard (France 2004:177). Since the medical ecology of disease management is the framework for examining each adolescent's beliefs and behaviors, the interviews must be semi-structured and open-ended to permit the adolescent to discuss those cultural aspects of his or her environment and social relations that he or she considers relevant (Sankar et al. 2006: S59). Open-ended interviews may also foster feelings of control for the young people, who, like women, "still feel powerless, without much to say" (Reinharz and Chase 2003: 77). The open-ended interview is also the setting in which adolescents are allowed to sketch out the big-picture issues – living with HIV, growing up and being an adolescent with HIV (identity formation), and revealing the problems that arise in managing their disease. It provides the needed latitude for the participant to narrate his or her subjective illness experience (Conrad 1990).

Interviews with adolescents may include some stumbling blocks. Adolescence is a period of personal and social development, when young people are constructing identities and strengthening their sense of self, and if this is especially conflictual for

them, they may bring an antagonistic attitude to the encounter with an adult interviewer (Weber et al. 1994:43). Privacy and confidentiality may also be very important for youth, who are sensitive to peer influences and may be reticent about sharing certain things if they thought peers would find out (Weber et al. 1994:43). The assurance of confidentiality and a location for the interview that is safe may assuage the adolescents' concerns about privacy.

Qualitative studies of medication adherence among people with HIV are underrepresented in the adherence literature (Beusterien et al. 2008; Sankar et al. 2006). Adherence to medication remains a problem across the spectrum of diseases, including HIV (DiMatteo 2004), and points to the need to examine the social and cultural contexts in which disease management behaviors occur, and which affect if and how these behaviors occur. This qualitative study of adolescents with perinatally-acquired HIV is an acknowledgment of the complexity of young people's lives, and the methods employed will allow a range of questions to be posed – not just what a person does, but why, how, where, and when (Lehoux et al. 2006:2092). This qualitative research also allows these young people to express themselves on issues that they consider to be important in their lives and for their health, and insofar as the data reveal potential areas of improvement for their disease management, it is perhaps one of the most ethical things we can do for them.

Role of the Researcher: Reflexivity and Positionality

The management of HIV disease that is the focus of this study is an experience that I, the researcher, share with the research participants. While our experiences are not identical, this shared phenomenon of living with HIV may have an impact on the

collaborative aspect of the research, and allow for identifying dilemmas as they arise. The reflexive position of the research will be assumed insofar as it can provide “insights, impressions, ideas, and hypotheses...[b]ut insights and impressions are not knowledge; they are paths to investigation” (Salzman 2002:808). The study of adolescents’ management of HIV disease is not the study of a middle-aged woman’s HIV disease management, but my position as a fellow ‘HIVer’ may facilitate an empathic understanding of the factors that help or hinder medication adherence and other health-promoting behaviors. The intersubjectivity that obtains from the interactions of the researcher and the participants may enrich the data that are collected, but interpretation and understanding of the data will reflect empiricism, not reflexivity (Salzman 2002:808). It is not my intention to insert my experience and HIV identity into the research, but rather to recognize the standpoint from which I approach the research (Hendrick 2000). Likewise, my position as an HIV-infected individual, because of its potential influence on the research process, relationships, analysis, and recommendations, merits disclosure both to the participants and to any readers of the final research product.

Identification and awareness of one’s standpoint during the research process, particularly that position which is shared with the participants and is the topic of the research, is important because that facet could affect how the research is approached and how the interviews and other interactions play out. It could also affect the quality of both the data that is ultimately collected and its eventual analysis. One risk that I faced as an HIV-infected person is that of projecting, even indirectly, my biases onto the interactions. There was also the possibility of positioning myself as the ‘knowing or capable’ HIV-positive person against the adolescents’ ‘less knowing’ position. Researchers have

addressed the differences that separate adults and children by suggesting various adult stances vis-à-vis the children they are studying. Mandell cites three possibilities in which adults position themselves closer to the children's world in an inverse relationship to the authority they wield, the complete involvement in children's worlds being the "least-adult" role (Mandell 1988:433). Eder and Corsaro suggest what corresponds to Mandell's intermediate role, in which adults adopt a "form of detachment by avoiding adult roles of authority...[and thereby] reduce the inherent power imbalance between adults and children" (Eder and Corsaro 1999:527). The reflexive approach continually reminded me of the position I deemed best to occupy, and allowed me to compare it to the position I was occupying as the research proceeded. While I attempted to keep my position, both as adult and as HIV-positive person, at a distance from the "empiricist vision" (Gellner 1988; quoted in Salazar 2002:812) that guided the research, I reflexively recognized my role and the effect that it had on my approach and responses. Reflexivity throughout the research process therefore attended to the continual effort I made to give the participants primacy and maintain a collaborative partnership in which we shared authority (Etherington 2007).

Reflexivity, as a process throughout the research, is a tool that researchers can use to help them to remain aware of ethical issues as they arise; it is achieved by continually questioning the ontological and epistemological positions that they take as researchers in the research process (Guillemin and Gillam 2004). It keeps them aware of the relationship they have with the research, the participants, the context, and the data at every step of the process, so that ethical or other dilemmas can be clearly identified, appreciated, and addressed. One of the ethical dilemmas that are possible in research

with young people is the fear or discomfort that these participants may feel in expressing themselves, particularly when it involves disagreement or displeasure. In addition to the ethical dimension of protecting young research participants, this dilemma has implications for the quality of the data. Reflexively considering the situation involves questioning the knowledge and how one comes to know it (Guillemin and Gillam 2004). The power relations that exist – adult/child and researcher/participant – do influence the research process, and need to be clarified and revisited to ensure a fair and productive environment for children (Woodhead and Faulkner 2000).

There is an ethical conundrum in designing and carrying out research with a population considered to possess less power than adults and less power as participants than the researcher, while maintaining that this population does possess power and competence. The UN Convention on the Rights of the Child sets out in Article 12 that parties to the Convention must

...assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (UNCRC 1989).

The right to contribute to research, however, opposes to some degree the need for protection. The research process is composed of many steps that suggest varying power and partnership arrangement at different stages (Karnieli-Miller et al. 2009). Thus, for example, the selection of methods for a particular project, generally the domain of the researcher, might be one of the initial areas of collaboration in which participants voice their opinions and preferences regarding possible methods (Hill 2006). Some researchers, in fact, underscore the “child-centredness” of research and children’s involvement in “development and implementation of research” (Lewis and Lindsay 2000:

cited in Balen et al. 2006:31). Data analysis rests with the researcher, but validation of the findings may or may not include participant input (Karnieli-Miller et al. 2009). The structure of the research relationships may be drawn up at the beginning of the study, but as with the process of consent (Helseth and Slettebø 2004), power sharing and level of participant participation may also need to be renegotiated during the project. Reflexivity on the part of the researcher includes asking herself about her role at different stages, and thus her participants' roles, and revisiting what she wants to know and how she will proceed in discovering it (Etherington 2007).

Florida Family AIDS Network's Perinatal Clients

The Florida Family AIDS Network (FAN) is an HIV/AIDS service program comprised of social service and clinical agencies that provide care to women, children, and families infected with or affected by HIV and AIDS in Hillsborough and Pinellas Counties in west central Florida. The program is funded by the Ryan White HIV/AIDS Treatment Extension Act, Part D, and has been in operation since 1992. The program currently serves about 1200 clients, who receive primary and specialty care at one of five clinical sites, and supportive services from one of two social service agencies that help clients maintain their health and continuity of care. Originally begun to address the perinatal transmission of HIV, the program has evolved to serve more adolescents and adults than infants and young children.

FAN includes pediatric clinical services for HIV-infected persons up to the age of 24, and provides these services to the majority of children and adolescents at two University of South Florida Department of Pediatrics clinics in Hillsborough and Pinellas counties. The FAN pediatric clinics have a policy to disclose HIV status to children by

age 13 regardless of parental preferences. Clinical staff work with parents, caregivers, social workers, and mental health personnel to develop a plan for disclosure of HIV status to children, and generally they begin the process and discussion well in advance of the actual disclosure. They also counsel children and adolescents on medication adherence and safer sexual behavior.

There are currently 163 perinatally infected persons enrolled in FAN, of whom 130 are between the ages of 13 and 24, and their demographic characteristics, age, gender, and race/ethnicity, are shown in Table 3.1. Figure 3.1 shows the current ages of the perinatal FAN clients and their HIV disease status. The numbers of perinatally infected persons in FAN mirrors the perinatal population living in Florida (Figure 1.3). The FAN perinatal population, as well as the study sample, is comprised of a higher percentage of girls than boys. Evidence suggests that mother-to-child transmission of HIV at birth is significantly higher in girls, though the precise mechanisms targeting females in utero are not known (Biggar et al. 2006; Taha et al. 2005; Thorne and Newell 2004).

Table 3.1 FAN Perinatal Clients † Asian, More than one race, Other, or Not Specified

FAN Program (N=163)	Number	Percent
Gender		
Female	94	58
Male	69	42
Race/Ethnicity		
Black	97	60
Hispanic	28	17
White	29	18
Other [†]	9	5
Age		
<2	1	<1
2-12	29	18
13-24	130	80
>24	3	2

The vast majority of FAN clients are living near the federal poverty level and are receiving Medicaid benefits. Among the perinatal clients, about 80% live below, at, or slightly above the poverty level, and about 74% are on Medicaid. Among the participants in this research study, 88% receive Medicaid benefits, and about 82% are at 120% of the poverty level or below. There are 14 perinatal FAN clients with private insurance, and only one of them is in the research study.

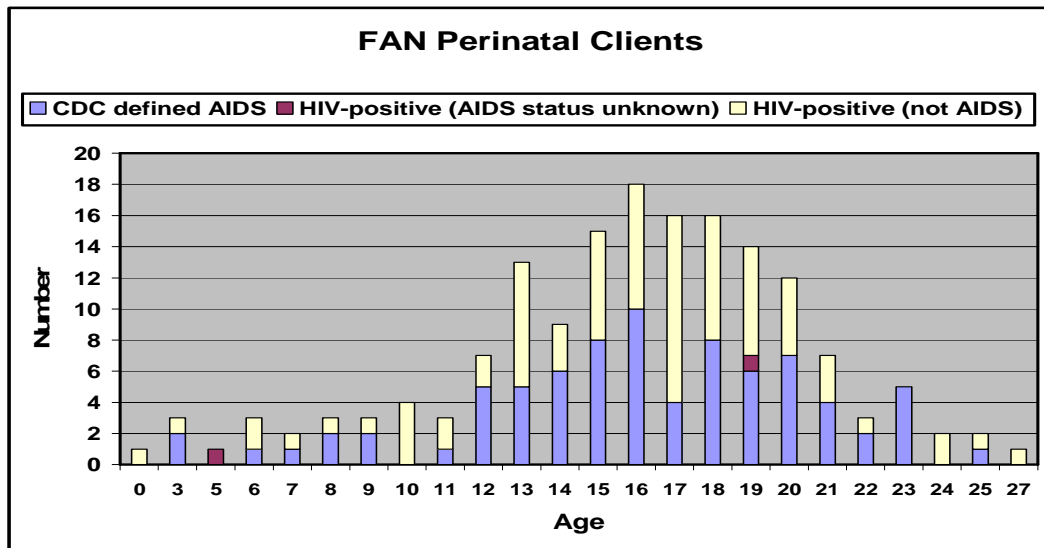


Figure 3.1 Current FAN Perinatal HIV and AIDS Clients (N=163)

Study Participants

Seventeen adolescents participated in the study, sitting for an interview lasting from thirty minutes to just under two hours, with most lasting for one hour. Participants were interviewed in their homes, at their case management agencies or other community-based organization, or at the researcher’s university-based office or other campus location. Table 3.2 shows the demographics of the adolescents in the research study.

Table 3.2 Adolescent Participants *Numbers rounded to equal 100

Research Participants	Number	Percent*
Gender		
Female	13	76
Male	4	24
Race/Ethnicity		
Black	12	70
Hispanic	2	12
White	3	18
Age		
13-17	10	59
18-24	7	41
Primary Caregiver		
Biological Mother	8	47
Biological Father	3	18
Other Relative	2	12
Non-Relative/Adoptive	4	23

These young people lived in households with a variety of primary caregivers and other relatives. None of the adolescents were living in a household with both biological parents. Eight of the seventeen adolescents were living with their biological mothers at the time of the study, and three were living with their biological fathers. One was living with an aunt and one was currently living with a cousin but had lived for most of her life with her grandmother. The four remaining participants were living with adoptive or foster non-relative mothers. The six participants who were not living with a biological parent had been with their caregivers since they were young children. Three participants had a biological parent with whom they were not living, but they knew and had contact with them. At least ten of the seventeen participants had lost one or both parents.

Recruitment of Participants

The study sample of adolescents was drawn from clients of FAN who were between the ages of thirteen and twenty-four at the time of the study and who were perinatally infected with HIV. Prior to recruitment, the support and permission to conduct this research were obtained from the principal investigators of the FAN grant and from the FAN administrator. Subsequently, the research proposal was presented for approval to the medical director at the USF pediatric clinic, and to the director or supervisor at the case management agencies that are part of the FAN network, and it was submitted to and approved by the USF Institutional Review Board.

The FAN program's perinatally-infected adolescents include 73 females and 57 males ranging in age from 13 to 24. Close to 60% of the youth are Black, 18% are Hispanic, 17% are White, and 6% are more than one race or 'other.' The research study was presented and discussed with the clinical staff at the University of South Florida's Pediatric Services in Tampa, and the FAN social worker at the clinic assisted in informing the adolescents about this research when they attended the clinics for their routine appointments. Additional collaboration was sought for recruitment of youth from the Tampa Hillsborough Action Plan (THAP) and the AIDS Service Association of Pinellas (ASAP), the two case management agencies where many of these adolescents receive support services.

The clinical care providers were asked to participate in the study, because they are a key source of information and guidance for these young people, in terms of their sexual, reproductive, and general health, adherence to medications, and the complexities of HIV status disclosure. A trusting relationship between the clinician and the patient can affect

the patient's success at assuming responsibility for his or her disease management. The five clinicians who cared for adolescent patients at the USF pediatric clinic were each asked to sit for a semi-structured interview.

One focus group of biological mothers was included in the study in order to explore the unique dynamic between biological mothers and infected children. These mothers are likely to be taking antiretroviral medications, will have had their own experiences, good or bad, with those medicines, and may harbor guilt about transmitting the virus to their children. How they view and approach medical treatment for their children may be dictated by these experiences, and could well be a factor in the knowledge and attitudes that their children will bring to their HIV management and adherence to medication regimens. The perspectives and experience of the parent, especially the biological mother, regarding medications, health care providers, social support and influence, and cultural beliefs can shed light on the child or adolescent's potential to accept and abide by the directives of the medical care providers (Wrubel et al. 2005).

Biological mothers of infected children were recruited from among those women who were FAN clients and whose records indicated that they had an infected child. From this group, recruitment was carried out through the case management agencies where they were receiving services.

Sampling

The purposive sample was made up of those adolescents who were informed of the study at the clinic or by case managers, and agreed to participate. The procedure for recruiting participants at the clinic involved informing each perinatal patient aged 13 to

24 about the study when they came to their clinic appointment. In addition, the social worker examined the clinic's appointment calendar and telephoned patients who were scheduled to attend upcoming clinics. When a patient agreed to participate, the social worker provided me with a telephone number and I attempted to establish contact with the patient or, if the patient was under eighteen, with the patient's parent. Of the eighteen patients approached at the clinic or telephoned by the social worker, two declined to be part of the study and one was hesitant and was not contacted again. Of the remaining fifteen, contact information was given to me for fourteen adolescents, and ten were enrolled and interviewed. The remaining four teens agreed to participate, but contact with the teen or the teen's parent was unsuccessful after several attempts. The mother of one of these four teens subsequently participated in the biological mothers' focus group, and at that time, she agreed to let her daughter be interviewed. Recruitment and enrollment in the study continued according to a schedule that allowed for four months of recruitment and data collection. When data collection was terminated, eleven adolescents recruited through the USF clinic had been interviewed.

In order to expand the possibilities of engaging more adolescents within the study population, the FAN case managers at THAP and ASAP were also approached and asked to call any of their clients who fit the study's eligibility parameters. In an effort to connect with adolescents within the time allotted for the data collection, THAP case managers were asked to call residents of Tampa, and ASAP case managers were asked to call St. Petersburg residents, before calling residents of outlying counties. In all, there were eleven active perinatal clients seen by three case managers at THAP, and four seen at ASAP by two case managers. Contact information for five THAP clients was

obtained, and four were contacted and agreed to participate. One was contacted several times, and messages were left for the caregiver, but contact with the caregiver was never established. At ASAP, contact information for two perinatal clients was obtained. Thus, from the two case management agencies, six clients were enrolled and interviewed. Data collection was terminated before any other recruitment efforts were made with the remaining clients at the two case management agencies.

All five clinicians who regularly cared for adolescent patients at the USF pediatric clinic were interviewed.

A list of thirteen biological mothers who had been actively case managed within six months of the focus group date was given to case managers, who were asked to contact their clients. The case managers notified me when a client agreed to participate. When seven women agreed to participate, enrollment was stopped. One additional woman had been contacted, but was unable to attend the focus group on the scheduled date. Six clients attended the group, and one was sick on the day of the focus group and could not attend. Four of the mothers who participated in the focus group had children who were interviewed for this study; two did not.

The participant groups and methods used are summarized in Table 3.3.

Table 3.3. Summary of Study Participants

Participant Group	Number of Participants	Methods Used
Adolescents	17	Semi-structured interviews Medication & adherence questionnaire Viral load & CD4 measures
Clinicians	5	Semi-structured interviews
Biological mothers of infected children	6	Focus Group

Limitation of Recruitment Process

An important limitation of the recruitment process is that the adolescents who were approached and asked to participate were those who were attending clinic appointments or had recent and regular contact with their case managers. Those who were not attending clinic or had been lost to clinic and social service care were not approached, and it is those who were hard to reach who were likely to have had very different management styles when it came to their HIV disease. Thus, the study participants represented a bias in that they were more likely to be more conscientious about their care and treatment.

Research Techniques and Data Collection

Upon agreement and consent to participate (parental consent and child assent were obtained for participants under 18, in accordance with IRB guidelines), the adolescents filled out surveys (Appendix A) before sitting for an in-depth, semi-structured interview. The interviews took place at the participant's home, at one of the case management agencies, or in a private room on the USF campus. Focus groups with adolescents were originally included in the methodology, but attendance at the first two scheduled groups was too low and the focus groups were removed from the methodology. However, the three adolescents who attended the first focus group sat for a group interview (due to time constraints, individual interviews were not possible). Each participant responded individually to the questions and probes. The three adolescents who showed up for the second focus group were interviewed separately.

Mothers (biological and adoptive) were present at four of the adolescent interviews. Three were present either intermittently or at the end of the interview, as the

interviews took place in the home. The fourth mother was present to aid her daughter, who had physical disabilities that made understanding her responses difficult. Her mother repeated answers when necessary, and when she added her own comments, concurrence was sought from the adolescent. While the presence of the mother altered the setting of the interview, each of the adolescents answered all questions posed and none indicated any unwillingness or inability to address any of the topics. Some of the mothers' comments were used, along with the data from the biological mothers' focus group, to provide family context in which adolescents experienced and coped with their HIV disease.

More than half of the participants were under 18 years of age, so as children, they were considered to be in the category of a 'vulnerable population,' and thus, in accordance with Federal Research Guidelines, special efforts were made to protect them. Every effort was made to assure the participants that they could withdraw from the study at any time without penalty, and could freely refuse to answer any questions of their choosing. In addition, and importantly, they were informed that the content of their interviews would not be shared with parents or health care providers. All data collected from the participants has been protected by storage in a locked file cabinet, which is secured in a locked office. All identities have been protected by changing participants' names, and any data shared publicly would be aggregate data or data using pseudonyms. Thus, respect for the adolescents, demonstrated by both maintaining their privacy and safeguarding the confidentiality of their information, was assured (Whiteford and Trotter 2008).

The FAN project utilizes CAREWare, a software program which connects all of the FAN agencies to a central database housed on a secure server at the University of South Florida. CAREWare contains client-level clinical and supportive service data, as well as demographic information, and is equipped to generate customized reports on demographic indicators and clinical performance measures. Reports of two clinical performance measures, the viral load and the CD4 (T cell) count/percentage, were generated from CAREWare data for the research participants.

Consent was also obtained from the women who participated in the focus group, and protection of data was assured. Women were reminded that all information shared in the group was confidential and should not be shared outside the group.

HIV-Positive Adolescents, N=17

FAN Data and Chart Reviews

CAREWare reports were run for all participants on demographic and clinical information, including age, ethnicity, HIV/AIDS status, primary caregiver, viral load and CD4 counts, and medication history.

Questionnaires

Questionnaires were administered to all participants, which included demographic information as well as questions about health care, medications, and adherence recall. Adherence recall used the Treatment Interview Protocol, or TIP (Marhefka et al. 2004), which was adapted for use with the adolescent participants (Appendix A).

Semi-Structured Interviews

Individual interviews provided the participants with the opportunity to tell their stories of living with HIV and managing their disease. It is well known that adolescents,

even those who are aware of their HIV-positive status, engage in risky sexual behavior, despite their knowledge of HIV and STI transmission and safer sex practices (Murphy et al. 2001). Since the transmission risks involved in unprotected sex are increased when HIV-positive people have elevated viral loads, the issue of medication adherence must also be addressed. It has been shown that perfect adherence to a medication regimen is rare even for adults, and tends to be more problematic for adolescents (Merzel et al. 2008). The issues surrounding adherence may be distinct for the perinatally-infected teens, since they have lived with HIV since birth and have had family members live with and perhaps die from AIDS. The interviews included questions about their attitudes and behavior, as well as external influences, regarding medication adherence.

The formulation of the interview questions was guided by the medical ecological perspective in which the research was situated (Brown et al. 2000; Williams et al. 2006; Steele et al. 2007), and by literature pointing to the main factors impinging upon the adolescent's adherence to medication and management of HIV disease – personal meanings and identity, social influences among family and peers, clinical care and relationships (Dodds et al. 2003; Pontali 2005), and attitudes and behaviors regarding their chronic disease and treatment (Pontali 2005).

In order to understand if and why they engage in risky medical and social behaviors, it was necessary to discover the meanings that these adolescents attach to HIV, their attitudes toward medication and adherence, and their behavior and communication within sexual relationships. The interviews probed for the participants' perceptions of risk, social pressures, and decision-making regarding health, and revealed why and when youth choose to take health risks, particularly those related to adherence. The reduction

of risky sexual behaviors in this population, while conferring health advantages on the youth themselves, is also aimed at protecting partners and stopping the spread of HIV. For individuals already living with HIV, particularly young people and those born with HIV, the notion of protecting others in a sexual relationship is perhaps less salient than that of procuring certain social benefits for themselves that may involve risky behaviors. Living with an incurable, stigmatized disease may color the decisions these adolescents make, so it was important to understand whether they experienced stigma, and how they felt about and coped with stigma and with their disease overall. Therefore, the interviews included questions about living with HIV on a daily basis and within their social environment.

Thus, the interview guide (Appendix B) included open-ended questions related to adherence, living with HIV, stigma, outlook and the future, sexuality, and risk, as well as questions concerning family, peer relationships and school, health care and relationships with providers, and other contextual aspects, such as social support and health care access.

Clinical Care Providers, N=5

Semi-Structured Interviews

Adherence is a topic routinely addressed by clinical providers and medical case managers, with whom HIV-positive adolescents have regular contact. The provider-patient dyad can be one of the most important relationships for the perinatally-infected patient (Dodds et al. 2003:43), and so the communication dynamics and the content and presentation of adherence and health risk counseling can be very influential in the acceptance of adherence responsibilities by the adolescent. Therefore, semi-structured

interviews (Appendix C) covering these topics were conducted with providers in order to ascertain the needs and possibilities for future implementation of such services.

Biological Mothers of Perinatally Infected Adolescents, N=6

Focus Group

Mothers had the opportunity to discuss their concerns, beliefs, and attitudes regarding HIV biomedical health care, antiretroviral therapy, and their own lived experience of HIV management. In addition, they discussed HIV disclosure to their children and their children's health care. The focus group guide is found in Appendix D.

Data Analysis

All of the adolescent and clinician interviews, as well as the mothers' focus group, were transcribed and entered into the qualitative analysis software, Atlas.ti, Version 6. Transcripts were read, reviewed, and coded; codes (Appendix E) emerged from the study's research questions and hypotheses, as well as from a review of relevant literature. Codes and accompanying quotes were examined in order to compare and contrast the experiences of the adolescents. The adolescents were then divided into contrasting groups based on the study's hypotheses: earlier vs. later disclosure, family acceptance vs. family ambivalence, peer support versus peer non-support, and so on. Analysis of the adolescent interviews, in keeping with the theoretical perspective of medical ecology, was also conducted individually in order to situate each adolescent's distinct lived experience of HIV disease management within his or her personal and social spheres of influence. The comparison analysis and the individual analysis were undertaken in order to identify the variables which had an association with the

adolescent's disease management, defined by the two most salient dependent variables, medication adherence and disclosure of HIV status to others, especially sexual partners.

Concurrent with the qualitative analysis of the interview data was the examination of two external biological variables for each adolescent: viral load and CD4 (T cell) count over time. Viral load was an important indicator of medication adherence, and CD4 count gave a general view of health status.

Analysis of the clinicians' interviews and the biological mothers' focus group transcript were done similarly to the adolescent analysis, with codes used as identifying themes. The information from these data was used as contextual background in the discussion of adolescents' experiences with HIV disease management.

Since time and logistics did not allow the inclusion of the participants as partners in each phase of the research process, it was especially important to affirm their lived experience of HIV disease by highlighting their voices in the analysis and discussion. By using their own words throughout, the particularities of their experiences were safeguarded, and acknowledged their social competence as well as the nuances of their social spheres of influence.

Study Limitations

This study was limited by the fact that the adolescents who were recruited and enrolled in this study were among those FAN clients who were scheduling and keeping appointments on a regular basis. They were approached when they came to the clinic or were called if their appointment was approaching. Disease management and its facilitators and obstacles might have been very different among adolescents who had not been in care for an extended period of time. Also, the seventeen adolescents who were

enrolled were all in good health, and all but one had fair to excellent immune function. Adolescents with poorer health indicators may also have revealed very different lived experiences managing their HIV disease.

The study was also limited by the small study sample and the fact that each adolescent was interviewed only once. In retrospect, particularly for adolescents, triangulated data collection, such as interviews supplemented by drawing, free listing, and pile sorting, would have produced more nuanced data, and the adolescents might have been more uninhibited in the drawing, free listing, and pile sorting exercises than in the one-on-one interview. Also, focus groups had been planned but did not materialize; they would have provided a venue for the expression of the culture of adolescence and elucidated some of the shared cultural domains of HIV experience, such as disclosure, stigma, and adherence.

CHAPTER 4: RESEARCH RESULTS

Adolescent Data

The adolescents' interviews revealed the complexity of their social, personal, and cultural environments and the factors that intersect in different ways to make each person's lived experience and management of HIV complex. While the small study sample precluded causal connections between a personal attribute, such as age at disclosure, or a medical element, such as understanding of medications and labs, and successful adherence, some factors suggested subsequent success at adherence and overall management of HIV disease. The myriad influences on adherence and disease management confirmed the need to look more comprehensively at the medical/ecological situation of each adolescent in order to discover how best to ensure success for these young people.

The primary indicator of the participants' management of their HIV disease was the level of adherence to their antiretroviral (ARV) medication regimen. All of the questions posed during the interviews were designed to reveal the factors in the individuals' lived experience which affected their ability to take their medications as prescribed. These factors will be presented in response to each of the study's hypotheses. Below in Table 4.1, the participants' names and ages, and their adherence level, as evidenced by lab measurements of viral load, are listed. Viral load is measured using an HIV RNA assay that generally measures HIV levels as low as 50 copies (or 48 in some tests) of HIV-1 RNA per milliliter, though more recently, viral load tests have been

developed that can detect even fewer than 50 copies (Pascual-Pareja et al. 2010). An undetectable viral load, which is less than the level of detection of 50 (or 48) copies, indicates successful viral suppression, and is achieved by a patient's practice of optimum adherence. Studies have indicated that at least 95% adherence is necessary for viral suppression (Bangsberg 2006), though there is evidence that lower adherence can achieve suppression, depending on the class of medications comprising the regimen (Maggiolo et al. 2005). Nevertheless, high adherence to medications is necessary for viral suppression and low adherence increases the risk of a detectable viral load, i.e., the failure to suppress the virus (Martin et al. 2008; Bangsberg 2006) and the risk of viral resistance (Veinot et al. 2006; Quinn et al. 2000).

If optimum adherence is being practiced and viral suppression is not achieved, then resistance to one or more drugs is suspected. Among the study participants, 47% had undetectable viral loads according to the available data. Among all of the perinatal patients at the USF clinic, 65% were found to be undetectable, according to one of the nurse practitioners, who had examined the clinic's data. The last two columns in Table 4.1 are participants' own recall of skipped medications in the two weeks prior to the interview and estimated skipped medications overall. This recall of skipped medications was recorded on the Adolescent Medication Questionnaire (Appendix A), adapted from the Treatment Interview Protocol (Marhefka et al. 2004).

Table 4.1 Study Participants and Adherence

Participant's Name ²	Age at Interview	Adherence (Based on VL)	Adherence Recall Days Skipped Medications, Last Two Weeks	Adherence Recall Days Skipped Medications Overall, per month
Paula	13	Undetectable ³	1	1
Lucy	19	Undetectable	0	0
Rachel	16	Undetectable	0	0
Valerie	16	Undetectable	0	0
Nina	17	Undetectable	0	0
Mark	14	Undetectable	0	1x/3 months
Bridget	18	Undetectable ⁴	0	1
Katie	22	Good ⁵	2-3	3 or more
Jeff	16	Good	0	0
Vanessa	16	Good	0	0
Angela	17	Fair ⁶	0	1x/2 months
Stephanie	20	Fair	2-3	3 or more
Diana	19	Fair	4 or more ⁷	2
Zoë	16	Fair	2-3	3 or more
Olivia	13	Fair	0 ⁸	0
Keith	18	Medication Stopped	N/A	N/A
Sean	20	Medication Stopped	N/A	N/A

The measure of adherence was taken from the participants' records of their viral load tests. Optimum adherence will maintain an undetectable viral load, that is, below 48 or 50 copies of the virus in the blood, unless viral resistance is ascertained. When the viral load spikes into the detectable range, it is likely that adherence has fallen. The viral load responds quickly to this fall in adherence, as evidenced by Bridget. Her viral load

² Participants' names have been changed to protect their privacy.

³ Undetectable is less than 48 or 50 copies/ml, depending on the commercial test.

⁴ Bridget had 9 consecutive undetectable viral load tests over two years, but her last two were detectable.

⁵ At least 2 consecutive undetectable viral loads and others under 1500 copies/ml.

⁶ Viral loads above 1500 copies/ml

⁷ Skipped medications in the previous two weeks were due to an unplanned 5-day stay at a friend's house.

⁸ Olivia's mother recollected having to remind her daughter often to take her medicines. However, Olivia's medications may have stopped working, as her CD4 count had decreased continuously to extremely low levels, in addition to her failure to achieve viral suppression. She began a new medication regimen shortly after her interview.

was consistently undetectable, when suddenly it spiked to about 7000 in one of her recent lab tests. Records show that she admitted to not taking her medicines regularly. Each of the study participant's viral loads, CD4 (T cell) counts, and medications were examined from the data entered into the FAN CAREWare database. The graphs displaying each participant's viral load and CD4 count/percentage over time are found in Appendices F and G.

Biological Mothers' Focus Group

The four main topics on which the discussion centered were mothers' disclosure to their children, the health care system serving them and their children, mothers' medication adherence, and concerns about institutions that were involved in research on HIV and treatments, vaccines, and cures. The women also alluded to stigma while discussing their experiences and difficulties living with HIV.

The mothers' responses and insights are integrated into the results of the adolescent interviews, as they relate to the perceptions and experiences proffered by the adolescents. Before the summary of findings in each section, additional results may be included from the mothers' focus group.

Clinician Interviews

The clinician interviews were conducted with two physicians, Dr. Flynn and Dr. Lane, and three nurse practitioners, Carol, Ann, and Ed.⁹ One of the nurse practitioners had a background in adult medicine, so his adolescent patients were all aged sixteen to twenty-four. The interviews elucidated the substance of the adolescent clinic visit, the clinicians' perspectives regarding the HIV management issues of adolescent patients, and

⁹ The names of the doctors and nurse practitioners are pseudonyms.

the relationship style of the clinician vis-à-vis adolescent patient. Aside from the physical examination, the clinic consultation included a discussion with the patient (and often the caregiver) of medication and adherence, lab tests, psychosocial issues, including sexual activity and risky behavior, and other issues specific to the patient. The encounters, according to the clinicians' descriptions, were comprehensive and typically longer than what might be expected in an adult clinic. Responses referring to how the clinicians communicated with their adolescents patients were examined to determine the extent to which the patient appeared personally engaged in his or her care and treatment, and the level of power and control that the patient assumed or was given.

Results

Adolescent Engagement, Provider-Patient Relationship, and Adherence (Hypothesis 1)

The level of engagement by the adolescents in their health care and the level of trust and interaction between them and the clinicians who regularly cared for them were hypothesized to have a positive influence on their adherence behavior. It was posited that the greater the youths actively participated in their care and treatment, the better their adherence would be. Likewise, greater trust and interaction between participants and their clinicians during their medical appointments would have a positive impact on their adherence. Hypothesis 1 reads:

The active participation of the adolescent in his or her health care and treatment plan, and the level of trust in his or her health care providers have a direct relationship on the adolescent's understanding of the importance of adherence and his or her acceptance of adherence responsibility.

The active participation of the adolescents in their own health care and treatment plan was measured by the level and type of responsibility they had in taking their medicines. More basically, an active rather than passive disease management style was reflected in their knowing the names and doses of the medicines they were taking, understanding what their lab tests meant, and being able to discuss viral load, CD4 count, and viral resistance. Provider trust was expanded during the interviews to cover the overall relationship that patients had with their HIV clinical providers, including the adolescents' rating of their providers' understanding of their HIV-related issues and challenges, the providers' efforts to discuss and understand the patients' lives outside of the clinic, patients' complaints about their provider or medical visit, and the patients' comfort and desire to ask questions.

Adolescent Medical Knowledge

Table 4.2 provides an overview of the participants' medical knowledge, which is discussed in the following sections.

Medications

The assumption that perinatally infected adolescents would know the names and dosages of their medications because they have been accustomed to taking medications throughout their lives was not supported by the participants' responses in the written questionnaire and in the interviews. Only about 30% of the participants could name their medications without looking at their medication bottles or a chart that listed and pictured all of the currently available antiretroviral medications. Thus, in and of itself, naming the medications was not associated with good adherence. Angela, a 17-year old, after consulting the chart and not being able to pick out her medications, finally said that her

mother knew the names and left the room to consult her. Most did know how many pills they took each day, though there was some hesitation by a few of the participants as they gave their answers.

Table 4.2 Adolescent Engagement and Adherence

Participant		Medical Knowledge		Adherence	
Name	Age	Knows ARV Names	VL, CD4, and Resistance Knowledge	VL	Recall ¹⁰
Paula	13	W/Chart ¹¹	VL, CD4	U	B
Bridget	18	W/Chart	VL, CD4	U	B
Lucy	19	Yes	VL, CD4	U	A
Rachel	16	Yes	VL, CD4, R	U	A
Valerie	16	Used List	R	U	A
Mark	14	Read Bottles	R	U	A
Nina	17	W/Chart	VL, CD4	U	A
Katie	22	Yes	VL, CD4, R	Good	D
Vanessa	16	Read Bottles	VL, CD4, R	Good	A
Jeff	16	Yes	VL, CD4, R	Good	A
Zoë	16	W/Chart	None	Fair	D
Angela	17	No	VL, CD4	Fair	A
Stephanie	20	W/Chart	VL, CD4	Fair	D
Olivia	13	No	None	Fair	A
Diana	19	Yes	VL, CD4	Fair	C
Keith	18	N/A	VL, CD4	N/A	N/A
Sean	20	N/A	VL, CD4	N/A	N/A

This finding is somewhat surprising, since all of the clinicians who provide care to these adolescents and were interviewed for this study said that, during most visits, they asked their patients to name their medications and reviewed the importance of adherence with them. In fact, some of the adolescents referred to the repetitiveness of the providers' questions about medications. One of the women in the biological mothers' focus group raised this issue in expressing her exasperation with the pressures of the clinic visit.

¹⁰ Adherence based on recall of missed doses: A = Never or less than once a month; B = Misses once a month; C = Misses twice a month; D = Misses 3 or more times a month

¹¹ Charts of all antiretroviral medications, with names and pictures of pills.

While Anita¹² described the visit as “overwhelming” because it included too many different professional encounters, she also thought it was a waste of time to ask the adolescents about their medications at each visit:

You got the nutritionist, you got the nurse case manager, you got to see the doctor, you got to see him. It’s just too many people...it’s so much pressure. Name your pills. You ask them that every time they come. If they don’t know the name of those pills by now, come on.”

The adolescents’ medication knowledge, the clinician’s and patient’s views of the necessity of reviewing medications at each clinic visit, and a mother’s perception that adolescents already knew the names of their medications indicate a divergence of opinion among patient, parent, and practitioner on what adolescents know and the instruction and guidance they continue to need.

Labs and Viral Resistance

Also reviewed during clinic visits were the patient’s lab results. When asked about the two main lab tests, the viral load and the CD4 (T cell) count, which indicate viral suppression and immune function, there was general familiarity by almost all of the participants. Three of them got confused by which count was supposed to be high and which should be low for optimum functioning. Only five had some idea of the results of their last tests, but 75% of the participants were aware of and demonstrated some understanding of these two measurements. Only two participants were unable to talk about them at all.

Of particular interest was the ability of the participants to discuss the importance of taking their medicines faithfully every day, and the connection of adherence to an undetectable viral load and to the risk of viral resistance. Only Katie, who was 22 years

¹² The mothers in the focus group have all been given pseudonyms.

old at the time of her interview, mentioned the term resistance without prompting, and two participants had a general, if somewhat inaccurate, idea of what resistance meant when prompted. When asked why it was important to take the antiretrovirals every day as instructed, none of the participants mentioned the threat of resistance, though Mark and Valerie did say that the medicines would stop working. All of the participants did say that their clinicians reiterated the importance of remembering to take the medicines every day. When I asked them if the doctor or nurse explained why, they could all give an answer, though their responses ranged from “it keeps the bad guys away” [Zoë, 16] to an attempt to explain resistance, “...the medicine will stop working...They say that my body won’t get immune to not taking them, and then it’ll stop accepting, it will reject them” [Vanessa, 16].

When I asked Diana, 19, if she had any idea of what would happen if she didn’t take her medicines every day, she replied with a chuckle, “Death.” She did, however, add that taking the medicines every day would “get your viral load up and my T cells back up or something like that.” This response showed an awareness of the viral load and T cells, though she confused the effect on the viral load, which would be lowered with good medication adherence. Lucy, 19, also was aware of the effect of the medications, saying they “keep my viral load high and I think my T cells down. I think that’s right. Is that right?” Again we see a slight stumble as she attempts to explain the effect on viral load. Paula, on the other hand, mentioned correctly that taking the medications keeps the viral load down and the T cells up, and Jeff understood the effects as well, with some probing. Rachel was able to explain resistance with some probing, and explained it this way, “I know they’ve told me that my body could start getting used

to my medication like too used to it and that it will reject my medication again and it will stop working because it's been working so well for so long, like that could happen.” Two girls, Angela and Olivia, simply mentioned that they would get sick if they didn't take their medicines every day.

Provider Explanations of Medical Concepts

The confusion and incomplete explanations with regard to viral load, CD4 (T cell) count, and resistance are somewhat surprising, given the clinicians' descriptions of how they explain these concepts to their patients. Each of the clinicians was asked if and to what extent they addressed lab tests and viral resistance in their encounters with adolescent patients. All of them said that they review the patient's viral load and CD4 count, providing more detailed information as the child ages. Two of the nurse practitioners gave interested patients health record cards with the patients' viral load and CD4 count so that patients could see their progress over time.

The explanations of these two measures ranged from a very basic description of target numbers to metaphorical or graphic representations. The detail of each clinician's explanation was somewhat varied, but generally basic, and seemed to depend on the interest and perceived ability of the patient to understand what these measures meant. Carol considered it very important for her patients to understand their viral load and CD4 count, and probed her patients for knowledge on which should ideally be low and which should be high, and then introduced specific numbers. She admitted that sometimes patients would still not be able to tell her their numbers, but she tried to get them to understand that they want an undetectable viral load and high CD4 count:

I kind of go a little bit into, like, “Well, tell me what your, what do I want your blood work looking like?” because I find that a lot of times it's very

characteristic of adolescents,...“if I don’t feel sick well I must not be sick,” so I try to really get them to buy into their numbers, like their T cells and their viral load...so I’m trying to make sure they understand, like, you want more than five hundred [T cells] and undetectable [viral load] and kind of make sure that they know where they are in that range of T cells, and then sometimes I’ll say, “Do you know what yours are?”...Because I pretty much go over them every time they’re in. I’ll be like, “Well, do you think they’re above five hundred or under five hundred?” And they’ll be like, “Oh no, I know they’re above five hundred because you say my labs look good every time,” so they kind of, they may not remember that they were 780, but they know that they’re in this really good range.

Ann described her discussion of viral load and CD4 count in a similar way, trying to involve the patients in the discussion of their numbers:

As they get older I definitely would go over their CD4 and their viral load, teach them about that...I explain what it is and definitely that’s going to be different levels for different people, for different kids and adolescents, but I pretty much, or sometimes most of mine explain it to me. I also will ask, “Now your CD4 what is that again?” And I try to have them give it back to me then, ’cause I can help correct it if it’s wrong. Or I’ll say, “Now is it supposed to be high or is it supposed to be low?”...So teaching about it, asking questions so that they can tell me what it is, and then going over their numbers. I’ll get a little tracker thing for kids or families who are interested. Some are, some aren’t, some don’t want to be carrying that around, some are really interested.

When asked if all of her adolescent patients knew what a viral load was, she responded, “They should definitely know what it is.” When asked if they knew what a CD4 count was and if they knew what their own CD4 count was, she said, “Yeah, and ideally, at the very least, they should know theirs [viral load] is undetectable and their CD4 is good. That would be great. If they could have a closer like, oh, 500 is their CD4, that would be great.” However, when I probed further for whether she thought her adolescent patients would know their count, she then replied, “I would say, I bet, know for sure the exact number or very close to the exact number, probably 40 to 50%, maybe 40%. Would know like, could say if they’re 560, could say five hundreds, I’m going to go with 40%.”

She did add the caveat that sometimes the patients who are doing extremely well, with numbers to reflect good adherence and good health, will not know their numbers, and this was indeed the case among several of the study's adolescents. This is because

when they're doing well...they seem less, they don't worry about it, so like I have some who are, they're just doing great but like if I asked her what her exact number is she would say I know it's very good, I'm undetectable, but she might not be able to tell me what her number is because at some point I think she's kind of said, well it's good and I'm not going to worry about that. [Ann]

Carol and Ann were not asked specifically if they discussed viral resistance with their adolescent patients. However, when Ann was asked whether her patients ever voiced any concerns or fears about taking their medicines, she did not point out any mention by her patients of resistance or the medicines not working.

Ed described viral load and resistance together in a boxing metaphor, which he said was very well received and understood by his patients. His description of resistance is particularly vivid, and was more detailed than the other clinicians' explanations. He also presented the concept in a way that his patients could relate to, and it bears quoting at some length in order to follow the thread to its conclusion, especially his inclusion of the somewhat difficult concept of resistance:

In the simplest terms I'll say, "Well, what happens when you take your meds?" and this is where I get into resistance, because I build all that into the same conversation. You know, "You're taking your meds and if you take them the right way, you're beating the virus down, beating the virus down, beating it down, beating it down, beating it down. When you have the virus way up to here, it's doing, it can do a lot of damage in your body, so the goal is to take your meds,...beat it down until the virus isn't even hardly thinking so well you're beating it down so good... down to such a low level that it's really not doing much. It's there, it's in your body, if you don't take your meds it's going to start growing again and getting really big but you're taking your meds, you're beating it down so it's not hurting you. You know, you're just keeping it smashed down as far as you can keep it smashed down." And I'll say undetectable... "we just say

undetectable, that means it's less than... thirty-eight... That means it's at such a low level that we just, we don't keep looking for it anymore because we don't really need to know the number, but you've done great, you've gotten it smashed down to such a low level, it's really just there, it's not doing the damage that it can do"...and so [I] get them to the point where they can finally do all that and explain it all to me.

...
"[B]ut if you are beating it down really good and you kinda stop taking your meds or start skipping doses, you're letting the virus come up a little bit so you want to just keep on beating it down...but when you don't do that, say you go hang out for the weekend, you go to a few parties, you don't take your meds, the virus is like ah, it's coming up again. So the virus starts coming up again but then you throw the meds on it again, you beat it down with the meds...and the virus is like,...oh shit, you know he's giving me the meds again. So then when it comes up again, when you stop taking your meds because you're partying for a weekend or you forget your meds...the virus is like, okay,...I know you just want to hit me with those meds again, so ***before he hits me with those meds I'm gonna change myself so when he hits me with those meds those meds aren't gonna work anymore, you know and then I'll say to people that's what resistance is. It's when you're not beating the meds down much anymore and you've given the virus the opportunity to think,*** because...when you're beating it down every single day, you're not missing any meds, the virus can't even think, ***but when you give the virus a chance to think, because it's smart, it's going to mutate and change itself so the meds don't work.***" [Emphasis added to specific excerpts on resistance]

Both physicians said that they discussed the viral load and CD4 count with their patients at each visit. They also said that they explained the concept of resistance. Dr. Flynn said,

I show them what's happening, try to explain in a simple way, like what resistance is, how does it develop and why it's bad for them to have a resistant virus. So we try to explain in simple terms of why does it happen, and yeah, we discuss about resistance. We don't go into the details, like the mutations or the numbers, but just what happens if the virus becomes resistant and what are the problems from that.

Dr. Lane said she discussed resistance with her patients in particular when a medication change was demanded (presumably because of resistance to one or more drugs in the old regimen) or there were problems with adherence. She went into greater detail in her

explanation, used imagery to present the concept of resistance to her patients, and sometimes showed them the resistance test results. She likened the virus and the medicine to geometric shapes that must be alike in order for the medicine to work against the virus:

What I try to do, you know, sometimes I kind of draw a picture of why a virus changed from a triangle, let's say, in the surface to like a square in the surface, so the medication that was targeting the triangle doesn't work and now we have to switch to this square...[O]r I show them ...the resistant test and because it's very graphic...I think that for some patients it's kind of an open eye of why, you know, I'm having issues, because when you see [it]... they give you different arrows and bars and stuff, but then on the right side usually has an interpretation... sensitive, resistant or partial susceptibility, and the resistance is...kind of highlighted so when you see your page, and you see that you are really not sensitive to most of the medications, I think that kind of puts the emphasis, yes, this is bad, you know, I've really blown most of my possibility for treatment.

Dr. Lane also said that she explains the level of adherence that is necessary for the medicines to continue to work and for the virus not to become resistant to them.

Despite all of the clinical details that the clinicians said they reviewed with their patients, including certain details at every visit, the clinicians' interviews nonetheless indicated that many adolescent patients do not have a committed interest in their clinical indicators and outcome measures, nor have they made the connection between these measures and their present and future health status. The clinicians also mentioned that there may be other priorities in a patient's life, issues that dwarf the importance even of their HIV, and prevent them from taking a keen interest in their health care. Several remarks illustrate this incomplete understanding:

It [a rising viral load] seems to make a difference maybe for a few patients, but for others, it's just like a number and a piece of paper...and they always go back to that argument, I'm still feeling okay, I don't feel bad, so maybe it's not so bad having a viral load, that the number looks very pretty on paper and you're [the doctor] really happy about it, but for

me [the patient], it really doesn't make a difference. I mean having a little viral load or having 50,000, I'm feeling the same way so why take it? Why bother. [Dr. Flynn]

Sometimes you want to...make them remember that a undetectable viral load doesn't mean that the virus went away, but it's just that we really suppressed the virus so we can [no] longer detect it by the regular, you know, routine methods in the lab. Sometimes that kind of, you know, they say, well maybe it actually went away. [Dr. Lane]

There definitely is an issue of the ones who are deteriorating, who've never really felt bad anyway, and probably haven't taken their meds much, like you know, they're not very adherent, but fortunately for a long time they've done really well. I'm sitting here telling you your T cells are going down, okay they're going down, this is a problem, you're below 200, and they don't feel a difference between when they were 600 or 500 or when they're 150, no difference. And they didn't take their meds when they were 500 and they are not going to take them when they're 150. [Ann]

Summary of Adolescent Medical Knowledge

In summary, despite the providers' emphasis on the medical aspects of HIV during the adolescents' clinic visits, most of the participants in this study did not display a detailed understanding of these concepts. During the discussion of why it was important to take their medicines every day, thirteen of the seventeen participants mentioned the terms 'T cells' and 'viral load,' and generally knew that the former should be high and the latter low. Two adolescents mentioned that if they did not take their medicines, they would stop working, and two simply said that they would get sick. In addition to the two adolescents who said that the medicines would stop working if they were not adherent, three participants had a good or fair understanding of viral resistance. Thus, the association between active participation in one's care and treatment and good adherence (as measured by viral load tests) was generally a positive one, where those more actively engaged had excellent or good adherence. However, it is worth noting that

that none of the participants displayed a confident knowledge of the medical aspects of HIV and the implications of adherence for future health outcomes and HIV transmissibility.

Adolescent Responsibility

The responsibility for taking antiretroviral medicines every day has been fully assumed by about half of the fifteen participants currently taking them, meaning that they do not depend on anyone to give them their medications or remind them to take them. All but one of these youth had undetectable or nearly undetectable viral loads, which strongly suggests very good adherence. Valerie, Jeff, and Diana, on the contrary, took their medicines with significant participation of the biological parent. Valerie lives with her biological mother, and together they regularly organize their pills. Valerie, however, is responsible for taking them, and said that she needs to be reminded only once in a while. The fact that Valerie's mother also takes antiretrovirals, appears to be diligent in taking her own medications, and is involved in her daughter's life, seems to be a factor in Valerie's success at adherence. Jeff's father sets out the pills for his son, and watches him take them, and this level of involvement again seems to ensure good adherence. Of all the participants who either have full responsibility or full involvement by a parent, only Diana, whose mother also sets out her pills, did not have perfect or very good adherence. Her situation and her mother's attitudes toward biomedical health care and antiretroviral therapy will be discussed further in the section on provider-patient relationships.

The young people who had problems with adherence were those for whom the locus of responsibility was less clear or those who were ambivalent about taking their

medicines. Olivia needed constant reminding and Angela said that her mother would “remind me if I like forget, like if I walk out of the house, she’ll be like, did you take your medicine. I’ll be like, oh yeah.” Zoë, Diana, and Angela mentioned that they had in the past stopped taking their medicines. Zoë said she was “going through something at the time. So I just stopped.” Angela said she stopped when she learned that her father had died (from AIDS) and felt depressed. Diana stopped only for several days, saying that she “just didn’t feel like taking them.” While all three resumed taking their medicines, emotional difficulties or indifference may still have an effect on their current, less than optimum, adherence.

Timing of Responsibility

The assumption of responsibility may also have been premature or overdue. Zoë, 16, has had full responsibility for her medications since she was thirteen, when her mother “gave me a choice to take it and not take it, so...she don’t remind me no more. It’s just me, it’s all on me.” However, her motivation for resuming her medications, after her decision to stop for a month, was not directed at her own health, but rather “just to keep my mom happy, and keep her from stressing... Just to make life easier for her.” Full responsibility for taking her medicines appears to be difficult for Zoë.

Diana is nineteen, and has not yet taken full responsibility for her medications: “I’m not sure about the dosage, ‘cause my mom, she does it for me.” She said that she wanted to perform this task herself, but “I try to tell her, let me do it myself, but she wants to do it...But I can’t learn if she doesn’t let me do it.”

It was conjectured that among adolescents living with their biological mothers, the disease management style and adherence behavior of the mothers might have an

impact on how the children assume responsibility for their own care and treatment. From the mothers in the focus group, there did not appear to be a relationship between a mother's adherence and her child's. Teresa, Joyce, and Nancy all spoke about the difficulties they had taking their own medications, whether because of side effects or forgetfulness, yet their children all had undetectable viral loads. Nancy was not vigilant about her own adherence, but she was about her daughter's. Anita confessed to being tired occasionally and not taking a dose, but overall, she was adherent and appreciated the importance of good adherence. However, she had two children, one of whom had perfect adherence and the other only fair adherence.

What seems to be more vital is the mother's attitude toward antiretroviral therapy and her involvement in the child's treatment and adherence. Donna was not convinced of the safety and necessity of the antiretroviral medications, and her daughter displayed laxity in her own adherence. Teresa was ambivalent about her own adherence, but said that her six-year-old son is accustomed to taking his medicine and understands that "it's his duty to take his medicine morning and night." However, one wonders how she will monitor her son's adherence as he gets older, because she also insisted that "you can't force somebody to take medicine. I don't care how old they are."

These examples, as well as comments from the clinicians, point to the difficulties that both caregivers and clinicians have in determining the amount of responsibility that an adolescent can handle and amount of involvement that they should have in their children's disease management. They find themselves trying to shelter these adolescents from the challenges of HIV, but at the same time, expecting or demanding that they assume responsibility for their medications. Among the clinicians, Ed, who sees older

adolescents, believed strongly that these young people would be more responsible for managing their disease if they were treated more like adults than like children by the health care providers. He emphasized his role in helping the patients to develop power and control in their disease management. He described the success he had with one patient:

He was a young man who was developing a disease identity, felt pretty hopeless, helpless because that's what happens with kids with chronic disease, they grow up feeling like this, you know, that they're, you know, dependent upon the health care system, their providers and everything. Their parents are worriers so they kind of overprotect and not let them kind of start developing but this one particular patient I was working with, when I first got him he had zero T cells and in a year and a half I just got three hundred and something T cells on him but for him it was changing the pediatric focus. He needed an adult focus; the pediatric providers, he wouldn't even come for their appointments because they couldn't shift from talking to him like a baby or a child or lecturing him like a parent would as opposed to giving him some adult skills, working some adult skills in, saying its up to you, dude, you know, and then he flew with that.

Both Ann and Dr. Flynn, however, cautioned that sometimes parents prematurely think that their adolescent children should be responsible for their medications, but the children are not yet ready to take on this responsibility without some continued guidance from the caregiver:

...what I find is sometimes, you know, the parents are like, they're fifteen, they're an adult, they need to know how to do that and I'm like, I understand, they're working to be an adult but as much as we want them to be able to do that, they're still learning, so then I do try to get the parent involved in still supervising it. [Ann]

...parents try to give away some of that responsibility and...they [adolescents] come to the clinic and they've always been undetectable and all of a sudden we see a big spike in the viral load and like, what's changed? Well I try to give up the responsibility and we say like, they're not ready. You're going to have to go back and watch every single dose; obviously they're not doing what they're supposed to be doing. [Dr. Flynn]

Some of the adolescents accepted the responsibility with aplomb. Thirteen-year-old Paula acknowledged that it was her responsibility to take her medicines, saying, “it’s not really his [father’s] job to remind me, so if he doesn’t remind me, I remember myself.” Lucy, 19, nicknamed her medications “my three special friends” and recognized their importance in keeping her alive and healthy when she described how she felt on the rare occasion that she forgot to take her pills, “I got scared ’cause I thought something was going to happen...That my count would go down really low. And fast.” Lucy was the only participant who expressed this kind of concern about being adherent.

Olivia’s case was complicated by the fact that her health care providers had decided that her medications were no longer effective. It is difficult at this point to know whether she was non-adherent or whether the virus had become resistant to the medications, though resistance itself could indicate prior non-adherence. Since her doctors had decided soon after her interview to change her regimen, it is probable that resistance was causing the lack of viral suppression. Nonetheless, during her interview, Olivia, 13, displayed little motivation toward managing her illness. Her adoptive mother, who joined the interview for the last several minutes, made it clear that Olivia needed constant reminding to take her medicines, and remembered on her own only when she wanted to demonstrate her sense of responsibility in exchange for getting something she wanted from her mother. Her mother also insinuated that Olivia was not at ease with the virus as part of her life. Her mother’s words are revealing and helpful, since Olivia was not very forthcoming during her interview. In addition to mentioning Olivia’s needing to be reminded to take her medicines, her mother also revealed that Olivia felt like she was the only child with HIV:

Why should I remind her when she knows she got to take her medicine? All the time. Not sometimes, all the time...She takes it every day, twice a day, but it's like, I shouldn't have to remind her, she knows she got to take her medicine. It's like, she don't want to take it. If I don't say nothing, then it's be done. She won't...[But] [i]f it's something she want, if she wants to go somewhere or whatever, then she'll bring the medicine. Like last night, you brought the medicine, right? Because she want to get her hair fixed today...

I tell her, she's not the only one. It's people out there that's sick and she feels that she's the only one and she's not. It's kids younger than her has it, but she just don't know who they is...I think...that she should like have, meet other people, let her know that she's not the only child of the age of thirteen, there's other kids, younger than her and older than her that has it, but they're not going to come out and say it, you know, open that that's what they have. Because they don't want anyone picking on them. But you're not the only one, that's what I keep letting her know.

Barriers to Responsibility

The clinicians mentioned additional barriers that hinder the adolescent's taking responsibility for adherence. Though they were not the focus of this study, it is important to note that psychosocial issues, substance use, and the physical side effects of the medications were mentioned as factors that could interfere with adherence among adolescents. For the perinatally infected adolescents, the sense of unfairness is a theme that clinicians hear in their practices. Even when they are healthy, the patients are reminded of their disease on a daily basis when they have to stop and take their medicine, and this can lead to rebellion and depression. Ann acknowledged the frustration of the psychosocial issues, because "it's the hardest stuff to fix." She also alluded to the complex lived experience of the adolescents and its effects on when and why they decide to become adherent:

And I'll tell you I have some who, they never take [their medicines] for years and like one day it clicks and they do it, and I can tell you, I mean it wasn't anything, I mean I've been doing the same thing for five years so it wasn't something I did. It was something, somehow,

between them and their life, and maybe something, somewhere, I maybe taught them along the way and it maybe clicked.

Ed focused more on the psychological issues that are a part of adolescence, including identity development and a period of rebellion. He believed that many adolescents, particularly the perinatally infected, wanted to “separate themselves from the disease, separate from the meds.” When asked at what age he saw this behavior, he said it was around the age of sixteen, but “usually by...late adolescence I can kind of get them over that hump.”

All of the clinicians agreed that mental health is a serious issue that needs to be addressed among the perinatal adolescent population. Asked to give a rough percentage of the adolescents that they think were currently in need of some mental health attention, they reached the same conclusion that half could use some help. Carol first cited 30 to 35% who have been diagnosed with a mental health issue, but then added that another 15% may be in need but not yet diagnosed. Dr. Flynn was at the high end, estimating that 60-70% of the adolescents had mental health needs requiring attention. Carol believed there was a “a huge need for more, kind of, high quality support groups and mental health...[that] their mental health needs are far bigger than their issues related to HIV.”

Problematic substance use was less prevalent, according to the clinicians, with most putting the level at around 10%, though Ann thought it might be around 20%. Dr. Lane added that of the older adolescents, she thought perhaps about 30% had tried drugs or alcohol. She added that in addressing adherence issues,

I don't like to generalize, but I would say that a greater part of the patients that may have an issue with compliance, do have some substance abuse going on, even if they're not necessarily, you know, getting in trouble with

it, you know with the police or stuff like that, but it's kind of a common practice and in percentage I would say I mean 30% at the minimum.

Summary of Adolescent Responsibility

In sum, taking responsibility for their health care and treatment meant good adherence for most of the adolescents, but only if the individual had the tools with which to be successful. One of these tools was comprehension of HIV and lab tests, as well as an appreciation of the importance of taking the medications every day. However, for some adolescents, active participation in their treatment may need to be tempered by active monitoring by the caregiver, and gradually increased as the adolescent matures. For others, mental health care and substance abuse counseling need to be provided.

Non-Adherence, Treatment Fatigue, and Treatment Interruption

Keith, 18, and Sean, 20, were two unusual cases among the study participants. They had stopped taking antiretroviral medications at the instruction of their health care providers, because they were not adherent to their medications. Sean's explanation was inaccurate: "I was doing good and they wanted to see if I could keep doing good off, so they just gave me the chance to stop and they said I was doing good without it." Keith complained to his health care provider that the medicines "make me feel like I'm going to throw up all the time, and they take away my energy. They make me weary, I had to lay, sleep all day, go to sleep so I could wake up and feel better." Since inadequate adherence can lead to viral resistance, the health care provider decided, in both of these cases, to interrupt antiretroviral therapy in order to avoid viral resistance and, therefore, safeguard their future medication options. When the clinicians who were interviewed for this study were asked whether they would ever stop antiretroviral therapy if a patient was doing well, they said they would rarely consider doing so, and pointed out that guidelines do

not recommend discontinuing treatment. They added that, during treatment interruption, there is increased morbidity and mortality, as well as “progressive immune deterioration.” One of the providers said that one might consider discontinuing treatment if a patient was clearly non-adherent but had relatively stable CD4 counts and low viral load.

Keith’s medications were stopped in January 2009. He was experiencing difficulties with his current regimen, and discussed this with his provider. He explained that he was directed to take his pills until his viral load reached very low levels, at which point the clinician stopped the medications and monitored his levels. However, from the available records of his viral load, it is not possible to ascertain viral suppression in January 2009. As of April 2008, Sean was not taking his medications and his medical chart indicated that he was not prescribed further treatment at that time due to his non-adherence.

As the graphs below indicate, their viral loads, though not suppressed, were somewhat steady at relatively low levels. Their CD4 percentages were at the low end of normal or below normal, the normal range being from about 30% to 60%. Thus, they were maintaining a relatively healthy status without their antiretroviral therapy, though Sean had been out care for about a year at the time of his interview, so it is unknown how his viral load and CD4 count had changed since his last medical visit in 2009. Keith, however, continues to show relatively low viremia without his medicines.

Studies on planned treatment interruption (PTI) demonstrate a rise in viral load in the weeks after PTI began and subsequent viremia stabilization, along with rapid decreases in the CD4 count and percentage and subsequent stabilization (Noguera et al.

2010; Castro et al. 2010). Thus, Keith and Sean appeared to be somewhat stabilized during their PTI, as of their most recent lab tests.

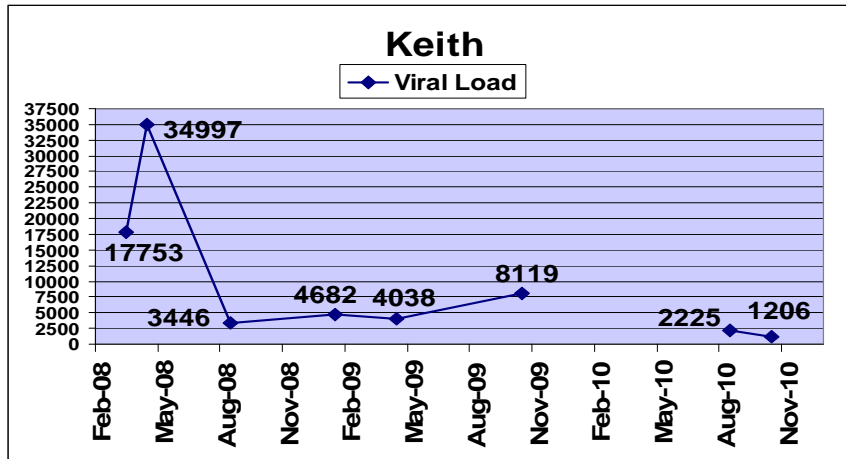


Figure 4.1 Keith's Viral Load, 2008-2010

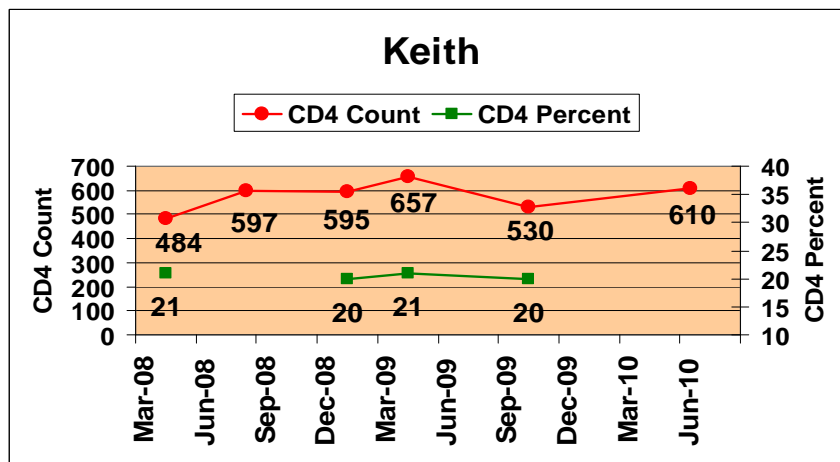


Figure 4.2 Keith's CD4 Count and Percentage, 2008-2010

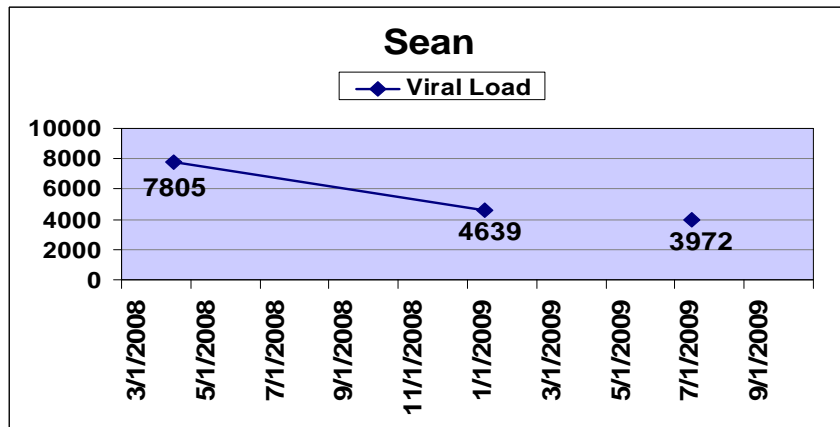


Figure 4.3 Sean's Viral Load, 2008-2009

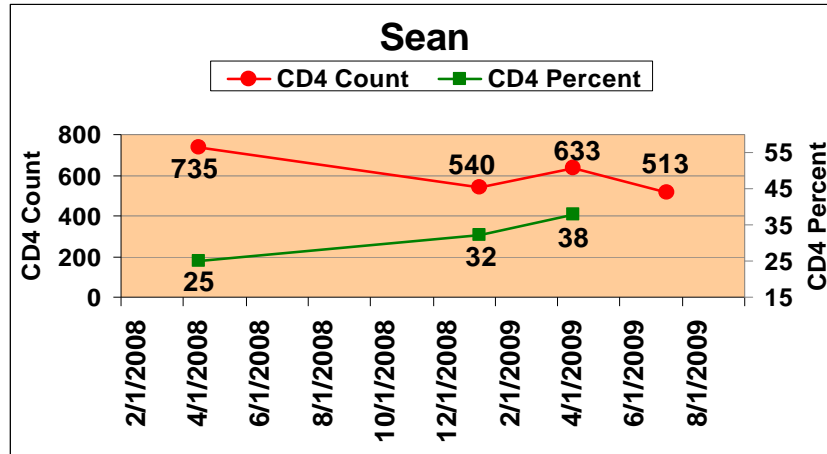


Figure 4.4 Sean’s CD4 Count and Percentage, 2008-2009

These two adolescents, Keith and Sean, evoke the issue of treatment fatigue.

Keith was especially frustrated with his regimen and its effects on his wellbeing. The lives of these adolescents have been defined by their medical experiences, especially frequent clinic appointments and daily medications. Parents, as we have seen, may be able to obviate this fatigue by continued involvement in and support of their children’s adherence. However, clinicians play an important role, too, through their medical instruction, facilitation of a sense of responsibility in their patients, and their help in resolving some of the problems (e.g., side effects, pill burden) that may lead to treatment fatigue.

The clinicians who were interviewed for this study had very different attitudes toward the issue of patient responsibility and continued adherence. Carol, taking the more pediatric focus, saw her role and message directed at the caregivers:

...the role of the caregiver at home is ultimately what makes you or breaks you....I think you have to kind of empower them [parents] and say, your message to them is that *not taking them [the medicines] is not an option*. It’s like, do you want to take them with dinner or after dinner or with apple juice or milk? There are certain things and absolutely, there can be lots of choices that are reasonable, but *not taking them is not an option*, and I think some of our caregivers, they get that, like you don’t have to have that conversation and it’s just clear and that’s probably how they

parent...I just think that message [is] that *not taking them is not an option*. [Emphasis added]

Ed also spoke to treatment fatigue and observed that, because of it, the perinatally infected were not as adherent as the behaviorally infected adolescents. He noted that rebellion tends to occur when adolescents reach about sixteen and are given or must take responsibility for their medications. In addition, he referred to the adolescent's identity development at this time, and the danger for an adolescent "to develop a disease-based identity because that can lead to dependent personality issues and a lot of helplessness." For this reason, Ed took a totally different approach, and since he sees older adolescents, he directed his actions and message to the adolescents:

I'm happier when they rebel a little bit than not rebel a little bit because when they rebel a little bit and stop taking medications for a while, I'll even give them a break sometimes, because at that point in their development they're saying, you know, I know I've had HIV, I've had it for my whole life, I don't want it to be part of my self-identity....I kind of expect that the adherence is going to be an issue with, not all kids. Some kids just continue on and take them, a lot of them in the teen years stop taking them and I think it creates a lot of anxiety in some providers when they do that, and if they're not particularly doing well it creates a little bit of anxiety in me too, if they're not doing well, but I know that once they get through some of these milestones, you know, more than likely they're going to start taking the medications again and I've actually seen that with a few of the patients here. You know, I think that's a very common issue, you know.

Dr. Flynn also brought up the realization by some adolescents of the lifelong nature of medications, which could lead to fatigue and the thought, "I want to see what happens if I don't take it." The problem with this treatment rejection is that sometimes the patients continue to feel well or to feel better, and it is then incumbent on the physician to explain that "yeah, you're gonna in the future, in the long term, it's gonna hurt you more than the short term benefit, if there's any to it."

The concern with the adolescent's decision to stop treatment or the physician's prescription of treatment interruption is that the adolescent's viral load may rise to levels that make him or her more infectious to sexual partners. This is discussed in Chapter 5.

Summary of Adolescent Engagement

The active participation of these adolescents in their health care and treatment was measured by their knowledge of medication names and dosages, lab tests and results, and viral resistance. What the interviews reveal to be even more important in terms of successful adherence is an internalized appreciation for what taking these medicines means. All of the participants admitted that the disruptions of daily living sometimes interfered with their medication schedules. What differentiates those with successful adherence from those who have problems is that the successful adolescents knew that they had to take the medicines regardless of the distractions, and found a way to do so. Whereas Vanessa, 16, took her pills everywhere and went into the bathroom to take them privately, Stephanie, 20, did not take her pills when she went to a friend's house. Olivia, 13, had to be reminded constantly to take her pills, whereas Paula, also 13, said it was her responsibility, not her father's, to remember to take her pills. Whereas Nina, 17, discussed her stomachaches and sleeping problems with her nurse practitioner, Keith, 18, stopped taking his medicines.

Overall, if the adolescents were actively involved and interested – took full responsibility, understood and accepted the importance of medication adherence – and had good support, they had better adherence. They are the ones who accepted the responsibility for managing their disease more completely, remembered to take their medicines, understood the importance of taking them, and were engaged in and

knowledgeable about their health care. The participants for whom responsibility was not accompanied by understanding and appreciation for what adherence meant had more trouble adhering to their medications.

Provider-Patient Relationship

The relationship between the adolescents and their health care providers had a weaker impact on how well these young people adhered to their medication regimens. Overall, the participants reported a good and trusting relationship with their health care team, and generally thought that their clinicians understood their particular issues regarding HIV medicines and adherence. Yet, among the adolescents who had a good relationship with their providers, some were considerably more successful at adherence than others were. Table 4.3 shows the participants’ ratings of their health care provider’s understanding of their personal experience with medications in response to the question:

On a scale of 1 to 10, how well does your doctor or nurse understand your issues, challenges, problems, and experience with taking HIV medications?

Table 4.3 Adolescent Rating of Provider’s Understanding

	1	2	3	4	5	6	7	8	9	10
	/	/	/	/	/	/	/	/	/	/
	1—Doesn’t understand at all----10 Understands everything									
Paula	9				Bridget	10			Diana	5
Lucy	9				Katie	10			Zoë	4
Rachel	8				Jeff	8			Olivia	10
Valerie	8				Vanessa	7			Keith	10
Nina	6				Angela	8			Sean	10
Mark	8				Stephanie	10				

The two teens who did not give a high rating to their providers’ understanding of their medication issues, Zoë and Diana, are the participants who were less successful at medication adherence than the others. In her interview, Zoë expressed disinterest in her

medical care, and in answer to a question about her lab results, she said, “it’s kind of confusing, so I just let my mom deal with it.” She also expressed annoyance with the repetitiveness of the clinician’s information and admonitions, saying, “she [the clinician] come in like every time I visit, it’s just complain about what’s happening to me. And she goes on and on for like ever...I know the stuff she telling me and she just go on and on.” The repetitiveness of the providers’ questions and explanations was also mentioned by Vanessa, Lucy, and Paula, though this did not interfere with their commitment to adherence. Bridget explained her take on this when she said,

...like when you’re young, they ask you, they’ll like constantly remind you that you have HIV, but as you like get older, like when you start to become more independent, they’ll start talking to you about protection and birth control and everything. ‘Cause they just put me on birth control...So it’ll change, once you get older.

Adherence counseling and discussion about medication regimens and problems are part of the clinical visit protocol, and the clinicians bring up adherence, lab results, and medications at most every visit in order to advance the knowledge of the patient according to his or her age and level of understanding. From the perspective of some of the adolescents, the process is not seen as educative, but redundant. This results in irritation and, sometimes, disinterestedness. Vanessa and Lucy, for example, knew the terms viral load and CD4 or T cell count, but were unable to state their latest numbers. This may reflect a lack of attention to what happens each time they visit the clinic.

Diana’s situation is complicated by the fact that her biological mother, with whom she lives, voiced ambivalent feelings about taking antiretroviral medication. Diana said that she is taking her antiretroviral medicines as well as alternative herbal medicines. She had changed health care providers recently, having seen her current doctor only twice.

She does not appear to have established a rapport with her doctor; when asked whether she talked to the doctor and asked the doctor questions, she replied, “Nope...I just listen.” While Diana knew the names of her medicines and had a basic understanding of her lab tests, she seemed to be less engaged with her health care than some of the other participants who displayed a similar knowledge. Her mother’s attitudes toward the health care she and her daughter received, and toward the antiretroviral medications, are likely to have exerted an influence on Diana’s commitment to her own health care. Diana’s mother was a participant in the biological mothers’ focus group, and her input will be discussed further in the section on family influences.

The influence of the biological mother on a child’s disease management is one of many aspects of a child’s environment that shape the child’s approach to his or her HIV disease. Some of the mothers in the focus group voiced dissatisfaction with the structure of the clinic visit (discussed below) and said that their children did not like going to their clinic appointments. It is noteworthy, though, that mothers who voiced dissatisfaction with certain aspects of their children’s health care had children who were extremely diligent with their medication regimens as well as children who were less engaged. The mother’s attitude toward her child’s health care seemed to affect the child’s attitude toward the clinic visit, but did not directly affect the child’s adherence.

The availability of different staff and services at the clinic, which some regarded as excessive, raises the issue of perinatal adolescents’ “care fatigue” and their changing needs. The clinicians mentioned that many of their patients’ needs could be addressed at the clinic, a convenience and advantage for many who otherwise would not have access to these services. However, the adolescents themselves, as well as some parents, referred

to the structure and content of a typical clinic visit as overwhelming, and this affected their satisfaction with the services and their willingness to keep their appointments. One of the nurse practitioners brought up this problem in his interview:

I think that has shown up on our patient surveys too, where they say, no, they don't like coming here, because they spend one, two, some patients are here three hours. By the time the provider is done obsessing, by the time they're shoved in to see the nutritionist and then they're shoved in to see a nurse and then the social worker comes in, that's, I think, that is cruel and brutal to do to some patients, to have them here for that long. [Ed]

Even though some patients think that the services are excessive, their dependence on the comprehensive attention to their needs becomes evident when they transition to adult care services. Many of them are not prepared to take the initiative that is required of adults if they want to have all of their needs met and questions answered. Four of the five clinicians underscored the problem and their role in it:

...a negative to that, though, is it's kind of like culture shock when they go to adult care, because there's not a half an hour long visit...and you know, my patients just call me directly...I think there's a huge need for them to really gain the skills that they're going to need in adult care, because, I mean, they don't know anything different than our little world and it's going to be a little bit of a shocker... And we normally just...let people reschedule, we don't ever turn people away. I think in adult care they're like, you no-show three times and you're done. We couldn't do that because there's nowhere else for them to go. [Carol]

By the time they see me they're getting quite a bit older, so they need to transition to adult care soon...It's kind of typical in this program, it's an acute problem. The youth don't transition well to adult care. When they get to adult care they have no skills to transition. They don't even know how to make their own appointments usually,...so I spend a lot of time in preparedness with them to get them ready to move into adult care, which I think, it takes a while for a pediatric provider to...shift gears...I kind of want to get the kids used to what it's going to be like when they get to adult care. It's not going to be coming to clinic and sitting in clinic and, you know, the provider taking an hour with them. That's just not gonna happen in adult care so ...I get them used to choosing two or so complaints and not a full list of issues that I've already talked to them

before about and kind of worked to empower them to take care of some of these things on their own. [Ed]

We over-shelter and protect our perinatal patients a lot...like here if they miss an appointment we call them, hey what's going on, what's happening? Or if they show up late we still see them and we're kind of more flexible and nurturing, but then once they move into the real world a lot of things are not gonna be there...[S]ome others have become too attached to the program and they go to the adult care clinics and they don't like them and they don't want to go back there. They want to stay with us, which is impossible, so yeah it creates an issue. [Dr. Flynn]

Usually we call, we send letters, we are very persistent with our younger patients, but they're [adult care providers] not going to call more than two times...[S]ometimes in pediatrics, we kind of are more like the mother and father of the patient, and then they are not going to have this in other settings. [Dr. Lane]

The clinicians' responses about the trust and understanding they had with their patients were generally comparable to the adolescents' assessment of clinicians' understanding of their adherence challenges. The questions were different, but the answers of both groups acknowledge that the providers understood at least some of the adolescent's experiences. However, the clinicians attributed some of this trust and understanding to the adequate length and the comprehensiveness of the clinic visits, aspects that some adolescents, as well as some of the mothers in the focus group, did not consider a positive aspect of their health care. In addition, while some adolescents found the clinicians to be repetitive, the clinicians considered it necessary, and were glad that they had the time to explain, review, discuss, and ask and answer questions, and could instruct their patients about medications and lab results at every visit, if necessary.

The latitude that the clinicians enjoyed in their clinic visits means that their acquaintance and their medical encounters with the patients were comprehensive. They indicated that many of their adolescent patients became very comfortable in discussing

their lives and their experiences with them. In this way, the clinicians had greater opportunity to look beyond patients' charts and attempt to see and understand the non-medical circumstances that can impinge upon individuals' ability, willingness, and means to undertake the necessary actions to manage and maintain their health. As Ed, one of the nurse practitioners pointed out, "for an adolescent, most of the issues are non-medical." This level of interaction and knowledge allowed for a far more in-depth encounter than patients normally have at adult clinics. Because the perinatally infected patients had generally been going to the clinic for years, the clinicians believed that they had a good rapport with patients and knew their patients intimately.

However, the clinicians had different views on how understanding they could be and how trusting their patients were toward them. They also had very different interaction styles. Regarding trust, understanding, and communication, one of the doctors, Dr. Flynn, rated his level of understanding of patients' experiences and challenges a seven (on a scale of one to ten, ten being a high level of understanding).

Carol, a nurse practitioners said,

They trust us a lot. I mean, I think I'm normally fairly aware if it pertains to, I guess, the part of their life which would affect their medical care, which is a lot of it. So yeah, I mean I think most of our patients are very open, and again we have more time...I can tell you where they work, where they live, their last partner's name, whether they use a condom, you know, fifty, eighty, a hundred percent. I mean, I think we get to know them pretty intimately.

Another nurse practitioner, Ed, answered, "I think I'm able to form a really good relationship with my patients. I would, I'd put me on a nine." On the other hand, the third nurse practitioner, Ann, described the level of trust among her patients as "the standard deviation curve" and rated her level of understanding of patients a five. She also

acknowledged, “You know, I understand some of it but you know, I’ve never walked in their shoes. I don’t really understand. Maybe I know a little, yeah.”

The stark contrast in interaction styles among the practitioners was apparent in two responses, one by a nurse practitioner and the other by a physician. The nurse practitioner, Ed, tried to shed some of the adult role in order to relate to the patients’ adolescent experience. He put it this way:

You know, I’m funkier, I use humor a tremendous amount in my healthcare approach to things, you know. So yeah, I think I’m pretty well trusted. The older they get the more they trust me, I think.

He also indicated his attempt to treat the adolescents more like adults:

What I do for you is this much, what you do for you is this much. You can come in, you can see me, we can shoot the shit, we can bullshit, but if you don’t do what you need to do to be healthy, you know, then that’s [referring to viral resistance] gonna happen to you, because I can do this much. Everything’s up to you and in your control now. Adolescents love that, you know, because that’s part of adolescence, that’s where they want to move into. They want to be adults, they want to have power over their lives.

Later, he added:

sometimes I’m provider, sometimes I’m life coach, sometimes I’m...perceived as almost a big brother, sometimes I get perceived, particularly from the kids who are looking for that, I almost get perceived as a parent sometimes.

The physician, Dr. Lane, took what appeared to be a more no-nonsense approach, emphasizing her role as the medical provider, who had to make the best possible decisions for her patients, while admitting that she could not understand her patients’ experiences completely:

...we try to understand, I try to be open, but unless you live the situations, I don’t think that you can really understand.... I hope I am in the higher end [of the rating scale] so that my patients believe that I am caring and

understanding their problems...I think that, you know, there are some patients that may be reluctant or some patients that really kind of connect more with their peers or someone from like a group or social worker... As a medical provider, you want to be able to understand your patient but you also, you're not necessarily the friend so sometimes, and that's what we try to build in our clinic is that there are these different layers [of services] so you know, I cannot be your friend because I want to be, I want to understand what happens to you, but I also want to make the best decision...[be] impartial...in what I'm actually going to do or going to tell you or make the best medical decision. You know, if you are emotional all the time involving the situation of the patient, sometimes that may not be of benefit to them. So you need to set up boundaries of where you are and how you provide help. But I'll say that the majority of the patients, because they have been coming...for the longest time and I think that they do have a good rapport with the majority of the staff.

Perhaps not surprisingly, the adolescents and clinicians had somewhat different perceptions of the level of trust and understanding in the patient-provider relationship, as well as different descriptions of and opinions about the comprehensiveness of the health care visit. The comments of the adolescents and the clinicians show that there is a conflict between, on the one hand, providing comprehensive services that patients need and addressing all of their issues as they arise, and on the other hand, treating the adolescents as responsible individuals, expecting them to understand and integrate medical information into their lives, and addressing them in a way that the adolescents receive as respectful of their age and maturity.

Summary of Findings for Hypothesis 1

Disease management requires a level of knowledge and acceptance as children enter adolescence and are expected to participate more in their HIV care and treatment. Whether or not their caregivers still had more responsibility for their children's adherence, the successful adolescents were those who had accepted that they had to take these medicines every day. If this acceptance was combined with knowledge of the

medical aspects of HIV and adherence, then they might be more likely to practice successful adherence. Those who were more ambivalent or who did not accept the responsibility for daily medication were less successful.

The provider-patient relationship among these adolescents and these clinicians was generally good, and the effect of this relationship on adherence was mixed. However, those who were less engaged with their providers were indeed the participants who had more problems being steadily adherent.

Family Dynamics and Peer Relationships (Hypothesis 2)

Family interactions and peer relationships provide the key backdrops for the adolescents' daily experience of HIV disease management. For the participants in this study, the activity of taking medications is, or is not, performed in the presence of family or friends. Thus, my second hypothesis was:

The lack of family stability (e.g., loss of parents or siblings to HIV) and peer support adversely influences adolescents' adherence.

Family Dynamics and Involvement

Support and Openness: Valerie, Jeff, Katie, and Mark

Greater family involvement, openness, and support led to greater success at adherence. Family structure and stability, however, did not correlate with the participants' success at adherence. Among those with excellent adherence and consistently undetectable viral loads, as well as among those who were struggling with their adherence, were adolescents who were in a stable household. In addition, fifteen of the adolescents, both adherent and less so, had lost one or both parents, never known one or both parents, or had been taken from a mother who had substance abuse problems. More than the stability and structure of the household, it appears that the caregiver's

involvement and openness about HIV led these families, and the adolescents themselves, to adapt to HIV in their lives and to incorporate the demands of the disease into their daily routines.

The clinicians also agreed that families who had adjusted emotionally to HIV and had made HIV disease management a part of the family's routine had adolescents who were more adherent to their medications. Ann's perception was that

our kids that were born with it who do well are generally, generally have been...in a family where they talk about it, it's part of what you do, you just take the meds whether you feel bad or good and so they've always felt good and they take their meds....I have some who live in very caring homes but the issues around the HIV are still very difficult for them. So they're safe, they're loved, but the family, there's still a lot of feelings about the HIV, whether it's mom or dad also has it or, you know, that they have trouble dealing with it and maybe mom hasn't always been great at taking her meds and she has trouble telling her child to or there's just general chaos. I have some who, there are very loving, safe, great homes...[b]ut the environment around their HIV is still not great as far as, like, taking care of that.

Dr. Flynn admitted that there is no "magic solution" to adherence for all adolescents, but he did note that patients who were successful at adherence were those who

told me it's to make it a routine like...when I go brush my teeth that's where I do it or when I have dinner. It's when they've been able to incorporate it as part of a routine in daily life. Or I think it's the most successful thing is like when they are able to incorporate it...that they don't have to think too much about it, when it becomes kind of an automatic thing.

Dr. Lane also pointed to routine and openness as characterizing the environment most conducive to successful adherence:

I would say that I think one is the family support so I think that if they learn from their parents or they have a supportive environment, you know, sometimes also there is a lot of secrecy, it's really hard, you know, if like there are ten people in the home and nobody knows about it, and they have the meds in a cabinet somewhere and need to hide to take them and have two minutes to try to do that and get a glass of water. And so if you have

family support – “I understand that it’s just normal, I take an aspirin, I take whatever, and I take these meds”....So in those patients that kind of get these medications as part of their routine, as I brush my teeth, I take the meds. So I think that family support is very, very important...if you have a happy boy or happy girl, they stay in a stable environment, most of the time the patient will adhere.

Valerie and Jeff’s parents are examples of involvement and support. Valerie and her (biological) mother organize their medications together, and Jeff’s father readies his son’s medications and watches him take them. Since Valerie has some physical disabilities, her mother is closely involved in providing for her daughter’s needs, including monitoring her medications. Both Valerie and her mother seem to have made room for HIV and its daily demands in their normal routines. Jeff has other adults in his life who also make sure he takes his medicines. When he is at his aunt’s house or his close friend’s house (whose parents know about his HIV), the adults make sure that he takes his medicines. He has both support and supervision that help him adhere to his medications.

Katie and Mark exemplify the adaptation to and acceptance of their HIV disease that comes from having mothers who have always been open and unashamed about this disease. Katie does not ever remember having to be secretive about her disease. Her description of her (adoptive) mother illustrates the no-nonsense and shame-free approach to HIV that is reflected in Katie’s good nature and acceptance of who she is:

My mom, she always was open about it. She never sugarcoated, she never hid it from us, and it was never, like, not a discussion or topic. We could actually be sitting at the dining room table, and ask her a question, and she never hesitated to answer, so she would tell us, you know... My mother is the free type of person, she’s like,...you be who you are, you are who you are, and you know what I’m saying, if it is that no one don’t like you for who you are, then screw them.

Mark's (biological) mother, who was present for part of Mark's interview, expressed the same sentiments about living with and accepting HIV, and being open with her son and not caring too much about what other people think:

I don't keep any kind of secrets from him... and I try to explain it to him...[M]ost kids don't understand and children fear something if they don't understand it...I don't live my life any different than you would live yours, my brother lives his, they all have to breathe the same. They're not Martians or anything like that, but for his sake [and] the children, you know, like if he cuts himself or hurts himself, he knows [what to do]... I'm not ashamed of what I have. It's a mistake I made when I was a child and the first thing I will tell anybody, this is why, I was straight, I knew for years ...yes, you can get it, yes you do need to use protection, this and this and this, and don't hide it. That's the first thing that comes out of my mouth.

Ambivalence and Silence: Zoë, Diana, and Stephanie

Many of the families displayed ambivalence and less involvement in their children's disease management. Others either did not talk about the disease or were careful to keep the subject within the bounds of the household. Zoe and Diana had problems with adherence, and both were in families where the mother had either relinquished responsibility or felt some uncertainty about how best to exercise responsibility. Stephanie and her family appeared to try to normalize life by not talking about her disease.

Zoë said that "until I was thirteen, it was my mom who had to tell me when to take it [the medications] and how to take it. But after that it was like, she like gave me a choice to take it and not take it." When asked if she was now taking her medicines herself, and whether her mother reminded her, she responded, "she don't remind me no more. It's just me, it's all on me." Yet Zoë, now 16, deferred completely to her mother in matters concerning her health care. When asked if she knew what her viral load and T

cells were, she responded that she did not, but when probed about whether the doctor told her what those numbers were, she said, “They tell me, but it’s kind of confusing, so I just let my mom deal with it.” Later, she explained what made her resume taking her medications after stopping for a month, she said, “I started realizing what I was doing, ‘cause she [her mother] was, she said, she said, I’m not going to deal with you no more, let God deal with you. So that made me feel kind of bad, ‘cause I was hurting her. I wasn’t really thinking about her at the time. So I started taking it.” Zoë’s disease management reflects a keen dissonance in her understanding of, engagement in, and responsibility for her health. She has assumed responsibility for taking her medications, but not for engaging in her health care and treatment during her clinic visits. Her engagement in the management of her HIV disease seems not to be so much for her own benefit as it is for her mother’s benefit and mollification.

Diana’s adherence seems to have been influenced by the ambivalence her mother, Donna, expressed about the merits and safety of antiretroviral therapy. Diana’s knowledge of her medications and familiarity with viral load and CD4 counts, coupled with her mother’s support and stable family life, might have helped her to maintain good adherence. However, her mother’s decision to stop taking her own antiretroviral medications in favor of herbal remedies, may have influenced her daughter’s attitude toward the medicines she was prescribed. In the mothers’ focus group, Donna voiced serious reservations about the health care system, though she did not say that her daughter had stopped her HIV medications. She only said that she used herbal therapies to treat some of the side effects of the medications. Nevertheless, Donna was dissatisfied with the care provided by the health care providers, and was extremely critical of their

treatment towards her. She was also very doubtful about the veracity of public information about AIDS, AIDS vaccines, and an AIDS cure, and voiced her belief about political and economic motives underlying the cause, potential cure, and treatments of AIDS. Her distrust of the system, as well as her belief in the toxicity of HAART, may be having an effect on how Diana approaches her own HIV disease management.

Stephanie seemed both engaged in and knowledgeable about her health, lab tests, and medications, but still seemed to be having difficulty maintaining good adherence. Of interest in Stephanie's case is her family history. She mentioned several times that she knew nothing about her biological mother and she lived with relatives in her home country until she was fourteen. Her biological father was in the United States and Stephanie relates her coming to join him here in this way: "...[M]y dad was in America. I was the type of children my dad never wanted. So the only reason I came to America is because of my stepmother. The first time she saw me she knew I was my dad daughter. But my dad didn't want to believe that I was his daughter." In addition to her father's initial ambivalence, and her early family instability, Stephanie said that there was little talk of her HIV in the home. While she maintained that her family treated her "just like I was a regular person, just like every, they don't treat anybody any different," the fact that "My dad just, we just live in the house just regular, none of the family never mention it" seems to indicate some reticence to confront and accept Stephanie's HIV. When asked if her family ever mentioned her disease, she said, "Yes, they ask me how my low level is [presumably meaning, how low my viral load level is], and I tell them...[m]y blood, how my like my blood thing is. How my labs, how the virus is doing." Beyond that,

Stephanie insisted that she was doing well because she didn't think about her HIV that much, and no one reminded her of it.

Effects of Stigma on Family Dynamics

The women who participated in the mothers' focus group did not bring up the subject of stigma, but they shared anecdotes that intimated both felt and enacted stigma (Scambler 2009; Lekas et al. 2006) in interactions with their families. The women were asked to describe the circumstances of their own diagnosis, how they reacted, and whom they involved initially. Rita was married and had a four-year-old daughter when her husband was diagnosed. She and her daughter were tested subsequently. She described her reaction and those of her family and in-laws:

My initial reaction was complete and utter disbelief....My family reacted, I think, well during the circumstance. ***My husband's family reacted terribly and we don't speak to this day.*** [Emphasis added.]

Teresa exhibited the secrecy that continues to mark this disease, even within families:

I was actually diagnosed when I was having my son. I have five kids and he's the baby...[A]t the time my son was born, I had my father, my mother, and my sister, 'cause those are the only ones that I have down here. I had told my older sister and my youngest aunt and that was it. So basically nobody else know. ***My other four children, they don't know.*** They know we take, me and the baby takes medicine, but they don't know what it's for. [Emphasis added.]

Anita's reaction of denial and anger certainly characterizes other diseases, but is especially prevalent among those who have HIV:

I didn't tell them [her family] right away. ***For a while I ran away from it, and was in denial.*** And I started using drugs and staying on the streets a lot. I didn't want to deal with it, and I was in a very abusive relationship at the time, so it was just a lot going on. He was in denial, he didn't want to admit it, and he didn't until he died. I was very angry about it. I was very angry at him. [Emphasis added.]

Peer Relationships and Support

Culture and Stigma in Peer Relationships

Peer support for the participants in this study is suggested by the number of friends or other individuals in their social network with whom they have shared their HIV diagnosis. The data show that those who have less peer support, as evidenced by their confiding in very few or no friends about their HIV status, generally had more difficulty with their medication adherence. This should not be interpreted as a causal factor in adherence, but rather may be a reflection of the fact that those who are less adjusted to and accepting of their own disease status are both less adherent and less likely to share their status with others. Only these tentative correlations, and not causality, could be suggested in this study with its small sample size. That said, two of the young women who had undetectable viral loads and were thus very adherent to their medications also had not disclosed their status to anyone, so the correlation between peer support and medication adherence represents but one of many possible facilitators in an adolescent's efforts to assume responsibility for his or her disease management.

The adolescents' discussion of disclosure to others revealed the social world of adolescence as well as cultural mores surrounding family privacy and AIDS as a stigmatized condition. The decision to disclose or not to disclose centered around the issues of trust and normalcy, as many decisions about sharing do in adolescence. The participants who shared their diagnosis with a friend all talked about trusting that friend to keep the information secret. Those who did not disclose to any friends mentioned the risk of having their information publicized if they told anyone. The following examples demonstrate this:

Because kids are immature and like, they'll spread it around. [Angela, 17]

Because then they'll tell the whole school...They would pick on me.
[Olivia, 13]

Because I don't want everybody to know, 'cause everybody might talk,
send it around...I don't like, I don't want everybody in my business.
[Jeff, 16]

You tell somebody, they'll go run back there, run back to that person and
now the whole world knows. [Sean, 20]

In addition to just wanting to keep their business private, these young people feared the stigmatization that accompanies an AIDS diagnosis. The participants were asked about the knowledge and attitudes of their school mates, and several mentioned their peers' scorn were they to learn of a friend's AIDS, as well as the use of AIDS as an insult toward those who were different or those who demonstrated an understanding of AIDS. Paula, who was knowledgeable about and comfortable with her diagnosis, especially at her age of 13, nonetheless denied her status: "just 'cause you know something about it, just 'cause you know a lot about it doesn't mean you have it, but I do have it, but I don't want the whole school knowing." Zoë discussed her experience with a boyfriend and other peers:

Well, I had a boyfriend, but it's like, if I asked him like certain questions, like what if, and he was like, if that was so, I couldn't be with a girl like that, so like, three months later I broke up with him. And then I asked my friends, what would they do, and they was like, I couldn't hang around no one who had it, so I just left it alone, and just kept it to myself.

Keith echoes this idea of people's wanting to keep their distance from people with HIV.

He said,

And the type of people that I hang around and I have friends with? Some of them is not the type that I tell, because of their mind frame and the way they think. Because once a black person like, the ones I hang around, hear about a disease or something, it's like oh, well, I can't be around you, I

can't, I don't know, I just got to be my distance. 'Cause they fear that if I cough in their face, something going to go wrong.

The stigma and secrecy surrounding a subject like AIDS was experienced very differently among the adolescents in this study. Rachel, sixteen at the time of her interview, and Mark, who was fourteen, were the only participants who construed the secrecy about their HIV status as a lie. More than once Rachel voiced her unease with keeping her status a secret from people: "I was just like, I don't need to lie to him anymore. Like I've lied to so many people it bothers me." And at another point: "it was like I just felt like I was hiding a large part of my life from him so I decided that I was going to tell him." When asked what the worst thing about having HIV was, Rachel replied,

I don't know, I mean one thing that's always bothered me is having to lie to people that I know. It's so secretive that it's like, and it doesn't even need to be, just the fact that it has been in my case, I guess. I wouldn't say that would be the worst thing, I would say that's the thing that bothers me the most.

When Mark was asked what the worst thing about taking HIV medicines was, he replied, "Whenever you just met a friend that they want you to spend the night you have to take your meds over there and they ask, why you gotta take that for? Then you don't want to lie to them."

Katie was very open and comfortable about her diagnosis. This seemed to be a consequence of her adoptive mother's openness and conviction. Even though Katie admitted to keeping her diagnosis from one boyfriend, overall she characterized disclosure thus:

I told other people if they asked me. She never told me that I didn't have to tell, you know what I'm saying...If they can't accept me for me, then oh well, if you don't like me. That's why I don't, I'm an

open, free person about my illness. That's just it. It's like I'm not going to sugarcoat who I am or what I am. Nothing in this world can stop what's going on in my body, besides me taking my medicine and doing what I have to do for myself, but someone else's opinion about it doesn't even matter, because if you don't like me because of that, obviously it's not a good thing, right?

Lucy, on the other hand, had no desire to share her HIV status with any of her friends. When asked to give a reason for not telling a friend or friends about her HIV, she gave an answer that reflected the nature of cultural beliefs: she pointed out the way things are rather than giving a specific reason for her silence. At first, she responded, "I don't tell people." When probed for a reason, she said, "Cause I choose to keep it to myself. As I think of it as a secret that only I can share it with my mom and my sister." Stephanie echoed the secrecy surrounding her diagnosis when she said, "I would not let my friend know I'm on medicine. Because my parents, even at the house, my parents doesn't even mention it, why would I even try to let my friends know that I'm taking medicine." Vanessa said she did not think she would ever tell anybody, even as an adult, because it was "none of their business." She conceded that she would make an exception in the case of a sexual partner: "Yeah. That's the only way I'm going to tell."

Of the ten adolescents who talked about what it was like to share their status with someone, six made a point of including how the virus was transmitted to them. They all mentioned being born with it or having gotten it from a parent. Nina said, "I told him I was born with it and that *it wasn't my fault*" (emphasis added), when she disclosed her status to a romantic partner. Keith's girlfriend, upon learning his diagnosis, told him it was not his fault. While this may infer a feeling of blamelessness, nonetheless, most of the adolescents still refused to share their status with others. They already perceived the general stigma of AIDS and presumably did not think that they would be accepted even if

they made it clear that they were not responsible for contracting the disease. Thus, for both those who disclosed with the disclaimer that they were born with it and those who did not disclose, the perception of stigma was salient.

The secrecy surrounding the adolescents' HIV status has had a logistical effect on adherence, in addition to its psychosocial sequelae. Diana, Angela, and Stephanie mentioned choosing not to or forgetting to take their medicines when they stayed over at a friend's house. Vanessa, on the other hand, maintained that, "I take them with me everywhere because I never know if I'm going to be back in time to take them. So when I take, I always get a little bag, and I put it in there. Then I get water, bottled water, and I take it." When asked what she did if people were around, she said simply, "I go in the bathroom [to take the medicine]."

Thus, while it would seem that support from friends would facilitate adherence, the attitudes toward sharing personal information about a stigmatized condition seemed to take precedence over this support, so that some of the adolescents seemed more comfortable with people not knowing and could still be adherent, while others felt more at ease sharing their status. Even among those who shared their diagnosis with friends, however, there did not seem to be an accompanying supportive interaction that came from discussing the participant's illness. Diana was the only participant who said that having friends who knew her status "makes me feel like there are people that care. Like they're not going to discriminate." Yet even she said that she and these friends did not discuss it, and she did not feel the need to do so.

Sexual Relationships and Disclosure

Peer support is perhaps most important in sexual relationships, because both disclosure of HIV status and medication adherence are key strategies associated with reducing HIV transmission. All of the study participants, both the sexually active and those who were not yet sexually active, knew that the practice of safer sex meant using a condom during sexual activity. Table 4.4 shows the participants who have ever been sexually active, current relationship status, and disclosure of HIV status to partners. Paula and Bridget were included, because they had discussed disclosure to boyfriends but had not explicitly stated whether they were, in fact, sexually active. Of the six participants who were or had been sexually active at the time of their interviews, five had disclosed their status to at least one partner. Katie and Diana said that they disclosed to their most recent partners, but not to past partners.

Table 4.4 Sexual Activity

Name	Ever Sexually Active	Sexually Active not confirmed	Current Boy/Girlfriend, Sexually Active	Past Boy/Girlfriend, Sexually Active	Disclosed HIV Status
Paula		√	?	?	Yes
Bridget		√	No Boyfriend	?	Yes, after one year
Nina	√		Yes	?	Yes
Katie	√		No Boyfriend	Y	No (first) Yes (second)
Vanessa	√		Boyfriend, not sexually active	Y	No(Current) Yes (Past)
Diana	√		No Boyfriend	Y	No (at age 15) Yes (recent)
Keith	√		Yes	?	Yes
Sean	√		Yes	?	No

Katie described the discomfort she felt because she had not disclosed her status at the outset of her first relationship. She compared her feelings for this person to her feeling for her subsequent partner, whom she told about her illness right away:

“I could not tell him [first boyfriend] why I liked, I really liked him [second boyfriend], because he understood about my illness. He [second boyfriend] was not afraid of me, he accepted me for all of me, you know what I’m saying, which he [first boyfriend] did not know, but that was my fault, because I should’ve told him in the beginning, which made it so much easier with Matt¹³ [second boyfriend]. If I would’ve told him in the very beginning, it kind of would’ve made it a lot easier with us... I can’t believe I did not tell him, I can’t believe I’m in this situation, I can’t believe this, ’cause I’ve always been a person that just really was free and open.... But when it came down to this guy, I was like, why, why, why, why. Everybody I could always tell, why, what was so different about him. I don’t know, I really did care for him so much, and I think, I think was the fact that I let my emotions get the best of my brain, you know what I’m saying.”

We see that even Katie, who was very comfortable with her status, had a difficult time disclosing to a romantic partner.

Diana disclosed her status to her most recent sexual partner before they had sex, and they used a condom. When asked how often she used condoms, she replied, “All the time,” but when asked if she ever did not use a condom, she conceded that she had not used a condom when she was fifteen. She learned her diagnosis at fifteen, and said that she had unprotected sex after learning her diagnosis, at the time that she lost her virginity. Interestingly, Diana’s mother, Donna, had not been ready to tell her daughter that she had HIV even at Diana’s relatively advanced age of fifteen, insisting that her daughter understood, without knowing her diagnosis, the universal precautions that she must take in order to prevent HIV exposure through blood and sex. She said,

I always emphasized to her, “Diana, you know when you’re playing in the playground, don’t ever touch anybody’s blood,” and she learned that when she was like three years old. “And don’t let anybody touch your blood,” and she says, “I know, Mom,” you know, so she knew and she told me one time, she says, “You know, my friend is so stupid. She had sex with somebody and she didn’t even use a condom.” Now she didn’t know she was HIV-positive, so when they used to come to me and say, well, she has

¹³ Pseudonym.

to know because she can spread this now, I said she is very well educated. She knows not to have sex without a condom, 'cause she doesn't know she can pass it on, but she's, but she know, and they asked her all types of questions and they knew she was up to date on things.

Nina was in a long-term relationship (at least two years) with a young man who knew her status early in the relationship. Within a few weeks of beginning to see each other, Nina felt that she had to tell him her status. She described it this way:

...the first day, well, not the first day but like a couple of weeks before that I had the feeling I had to tell him, I had to tell him, I had to tell him. I had that thing stuck in my head, I'm like, no I gotta tell him so I told my mom and my mom was like, "Don't tell him, don't tell him yet. You're gonna lose him." I was like, no it's not that so and I told how I was like, I'm just gonna tell him, if he leave me, he leave me, I don't care. So I sat down with him, I told him and he was shocked. He was shocked but we've been through thick and thin.

Nina was just shy of eighteen at the time of her interview, so disclosure to her boyfriend occurred when she was no more than sixteen. With regard to protected sex, Nina admitted that her boyfriend did not always use a condom, but he understood the implications of his actions, and was tested for HIV regularly. The fact that she decided to disclose her status to a boyfriend when she was only about sixteen, despite her mother's admonishments, indicates Nina's fortitude and willingness to accept her HIV as a part of who she is. As we shall see in the next section, she was also one of the adolescents who learned her HIV diagnosis at a young age. This may have allowed her the time to adapt to her disease, and thus be more comfortable in disclosing to a potential boyfriend.

The cases of Keith and Sean were more problematic because they were not taking antiretroviral medications, were sexually active, and male-to-female transmission of HIV is more efficient than female-to-male transmission is (Stine 2003:212). Keith told his girlfriend of his HIV status at the beginning, and he said that he knew about using

protection. Yet, he admitted that condoms were not used every time they had sex, and his girlfriend had become pregnant, lost the pregnancy, and was, at the time of the interview, pregnant again. Sean had a girlfriend for about two months at the time of his interview, and said that it probably would not be a long-term relationship. For this reason, he did not disclose his HIV status to her, though he said that they used condoms during sex. He also was one of the participants who had told no one outside his family. When pressed about whether he could foresee disclosing his status to anyone in the future, he responded:

If I been with a girl for about two or three years, then I tell her. It's been so long why not?...If our relationship really good and she really like me and I really like her and we planning on being together for a long time, then I sit down and say hey.

Sean did, however, see a problem, including possible legal ramifications, with having a sexual relationship with a woman and not disclosing his status to her, but he could not see himself telling a woman at the beginning of the relationship:

Interviewer (I): What's the problem?

Sean (S): I'm having sex with her but not telling her what I got.

I: So why don't you tell her?

S: I can't do it.

I: You just can't do it. You would have to wait awhile. Why, what if you told her? Are you afraid to tell her? Would you be afraid to tell her? Would you feel embarrassed or like...?

S: I'd be afraid and be embarrassed at the same time.

I: Why, what would you be afraid of?

S: If I tell her that's gonna stop our relationship.

I: You think she would leave you?

S: Yeah, stop our relationship. Then she go back, probably tell her mom and dad, I was with him for such this long and he didn't told me.

I: And now he's telling you.

S: Now he's telling, the police get involved and I've been messing with her daughter.

I: So why don't you think it's a good thing just to tell her right at the beginning, then there's no problem?

S: She wouldn't want to be with me because I'm sick, I've got a disease.

In summary, the adolescents who were sexually active knew how to protect themselves and their partners during sexual activity, but they did not all practice safer sex, nor did they declare that they did or would disclose their status before engaging in sexual activity. These results point to the difficulty and fear of discussing a sensitive and stigmatized issue with sexual partners that all of the adolescents may face.

Clinicians' Discussions of Sexual Behavior

Adolescents are, however, prepared for the eventuality of disclosure and negotiation of safer sex through discussions with their health care providers. All of the interviewed clinicians reported that they addressed sexuality and sexual activity during their clinical encounters with adolescents. These issues included sexual preference, condom use, sexually transmitted infections (STIs), contraception, disclosure to sexual partners, and the legal ramifications of HIV transmission and non-disclosure.

The three nurse practitioners tried to approach the subject of sexual behavior within the context of the adolescent culture. Carol and Ann often introduced the subject of sex by first asking about the patient's life at school and with friends. Carol recognized that for these young people, especially those who may appear a little uneasy,

...somehow it's easier to talk about friends than yourself and I think that's done for a lot of different things as well, but I think if you can get a gauge of what's going on with their friends, and then they get a little bit comfortable talking about that. Like it's somebody else, then it's kind of an ease into what's going on with them.

Ann also recognized the importance of understanding the patient's social environment, and might begin the discussion by asking the patient if any of his or her friends had girlfriends or boyfriends. She explained, "That's something I lead in [with] because a lot

of times what their friends are doing is very reflective of what they're potentially doing, so those are my early lead-in questions.”

The adult nurse practitioner, Ed, also recognized that the patient's friends, and especially romantic partners, may influence their behavior. Because of the importance of safer sexual practices among the infected youth, not only to prevent transmission of HIV but also to avoid exposure to and possible infection with other STIs, the disclosure of one's HIV status and the use of condoms become primary considerations in a sexual relationship. Yet, these are difficult actions to execute, and may be fraught with anxiety, fear, and even danger. For this reason, Ed encouraged his patients to bring their partners to the clinic so that he could facilitate the discussion and provide information and explanations relevant to the couple's relationship.

Four of the clinicians said that they brought up the legal implications of not disclosing one's status or using condoms, and the fifth alluded to them by speaking of the “repercussions” of not using condoms. Florida statute 384.24 states that it is unlawful for any person with HIV, who is aware of his or her status, to engage in sexual intercourse with another person unless that person has been informed of the HIV and has consented to the sexual intercourse (Florida Legislature 2010). This complicates the sexual relationship, because it not only requires disclosure of one's HIV status, but ostensibly also requires that the infected individual obtain and retain proof of the partner's awareness and consent.

While all of the clinicians addressed the importance of disclosing one's status and using condoms, for both legal and health reasons, their responses to patients' fear, ambivalence, refusal, or just human error regarding condom use and disclosure within

their sexual relationships were markedly different. The two physicians took a more clinical approach, while two of the nurse practitioners were more instructional and disciplinary, and the third NP was realistic and direct. Though the interviews did not contain actual conversations that the clinicians had with patients, I think that they do reflect how they communicated the information to their patients. Examples of each clinician's style follow, and they raise the issue of how the clinician's style may affect how and what the adolescent shares with the clinician, and how and which messages are received by the adolescents. This will be discussed in Chapter 5.

I also try to do some sex education like how it can be transmitted, about protecting themselves or using condoms, both for females and males, addressing the issues about the law in Florida, like what happens...how you need to disclose...how to address talking to a partner...and all the different aspects, so that if they have questions about like sexual practices...a lot of kids have a lot of questions...We also provide condoms in our clinic. We give them free condoms and we also tell them the other places they can go.... [Dr. Flynn]

...“do you have a partner...or have you been sexually active?” and...I also try to relate that with disclosure, so I tend to be actually very up front with that. You know, “You really need to disclose your partner, because you can get in trouble, and your partner can make charges against you and all that.” But then we try to relate that to the protection that they need to use, so...“Because you have HIV, you are at a higher risk of getting other things that may be harmful for you, and in the same way that you don't want to transmit HIV, you also don't want to get other things that you don't want.”...You know, we kind of go over...“When do you think that you're going to be ready to be sexually active and...if you are in a long-term relationship and you think that you will be sexually active in particular with this person, you know that the disclosure should come.” So I kind of try to say, “You need to feel comfortable with the person that you're going to disclose your HIV status.” [Dr. Lane]

So what my message about that is, “This is what you should do and this is why. The person you're having sex with has a right to know that it's possible they transmit HIV. They need to realize why condoms are so important, but if you choose not to tell them you cannot have unprotected sex, you can't.” And I think some of the guys, and I just had a pretty in-depth kind of guy visit the other week...It's like I can almost see that he's

toying, he's never had sex before, but he's like right there...and he's undetectable, he's toying with having sex but having it not be protected. And it's like, "No, no, no, that's not an option," and not telling, and I'm like, "No, no, no, you can't do that." [Carol]

I try to do things like, well, what might be some reasons to choose not to have sex? And I try to get them to give me some ideas, and...then I try to then give something back. So... we'll talk about pregnancy risk...[w]e'll talk about sexually transmitted infections, of them getting another infection. We talk about it in terms of them exposing somebody else...[W]e get into disclosure... just emotional, definitely with some of the younger patients I'll talk about, you know, not just the risk of STIs and pregnancy but also, "When you go to have sex with somebody, that's a big choice, and is that the first thing you want, are you ready to do that?"...As far as disclosing to partners, I try to let them say what their concerns are about it and we try to talk about that. I do have a good little [information] packet and...sometimes I'll use the packet with them to try to talk about maybe getting ready for the process. [Ann]

...we get into the conversations too that are harder...because sometimes if they're sexually active...they'll say "Well, no, I'm having sex now and I'm not telling my partners ...because I'm just kind of fooling around with people, but I make sure that condoms are used, so I don't tell them." And I think the pediatric response to that may be, you have to do that, you have to do that, 'cause it's that parenting thing that they like to do...I'm totally different. I'm like...in the perfect world, people would tell each other that...that you have something that can be transmitted.... This isn't the perfect world and do people do that? No. It's great if you can, if you can't but you're having sex and people aren't going to stop having sex, just make sure that you use condoms, make sure that you're protecting yourself, protecting who you're with. Is disclosure as important if you're undetectable and you're using condoms, or you're using condoms? You know, that's a very personal decision that you have to feel comfortable with, and you have to see what's okay for you and what you can live with if something happens. [Ed]

Support from Other HIV-Positive Adolescents

A final significant detail absent in the interviews with regard to peer support was any talk about wanting or obtaining support from other adolescents perinatally infected with HIV. Diana's mother, when approached about this research study, had hoped that, by participating, her daughter might meet other positive adolescents, because until then,

she did not know any other infected young people. Beyond that, however, four participants mentioned having gone to a camp for HIV-infected children at one time in their lives. None of the adolescents brought up the issue of support from other HIV-positive adolescents, though not all of them were directly questioned about it. In response to a question about whether they would like that kind of support, Stephanie and Diana specifically said that they do not need it, though Diana toyed with the idea.

Stephanie: Actually, I'm okay. It's because my, I like, I'm really great with it, because my family doesn't make me feel, um, they never mention it, treating me bad. And I like it because they never mention it, and I feel kind of better because I don't think about it.

Diana: Might be good, but it's not going to help, 'cause I don't have a problem with it anymore. But the lady, I forgot her name, she just told me about the YES¹⁴ [Program]...I was going to try that out.

Summary of Findings for Hypothesis 2

The adolescents who were very adherent to their medications were those whose parents and caregivers were open and accepting about HIV in the adolescent and in the family. These adolescents also had adults in their lives who were involved in their disease management, or they and their caregivers had designated clear roles in the process of management and the youths were ready to assume these roles. The adolescents who had difficulty taking their medicines as prescribed were those who had less involved and less open caregivers and seemed not to be equipped with the medical knowledge and psychosocial resources to be independently responsible.

The support of peers was extremely low overall among the participants, because most had not disclosed their diagnosis to any friends, or had perhaps told one or two persons. Thus, their peer networks did not provide acceptance and support that comes

¹⁴ Youth Education Services.

with sharing personal details with peers and helps adolescents cope (Sherman et al. 2000). The ability to disclose this kind of information was also problematic for some of the sexually active adolescents. While adherence among those who had shared their diagnosis with peers was generally better than among those who had not, there was not a strong correlation, and it seems that the cultural salience of keeping secrets may have been more conducive to adherence than any potential help they would have gotten from friends. The problem with keeping the diagnosis a secret, however, was that it sometimes interfered with pill taking, as when adolescents were spending time at a friend's house or were involved in a social activity at the time when medications were normally taken.

Disclosure of HIV Diagnosis to the Child (Hypothesis 3)

Carol, one of the nurse practitioners who treats adolescents at the USF pediatric clinic and was interviewed for this study, underscored the importance of disclosure in the child's progress toward engaging in and taking responsibility for disease management:

...until I can use the word HIV or the letters HIV with the patient...I think once you can use all the language and all the terms and just speak freely, I think there's a shift...in like your history, you know. At some point I kind of turn this way and I direct the questions to the patient and I think some kids just naturally respond to that and answer and do the best they can and if they can't then they look at the parent. Or I'll look at the parent sometimes [and] the parent or caregiver doesn't really realize...and so they'll keep answering and you'll be like no, they can tell me how they've been feeling.

Children have to learn their diagnosis sometime and have been disclosed to at a wide range of ages, but the event is imbued with the fear, anxiety, and guilt that accompanies perinatal HIV transmission. This prompted the third hypothesis:

The timing and circumstances of disclosure to the adolescents have an impact on their subsequent adherence behavior.

The adolescents who learned their diagnosis at an early age could not, for the most part, remember exactly when the disclosure was made. When probed for an approximate age, most estimated an age of about five to eight years old. Only Mark remembered his age at disclosure, “because it was a week before my tenth birthday.” Thus, in Table 4.6, their age at disclosure is noted as less than or equal to age ten, and they were considered “earlier disclosures.” Since the clinics which are part of the Florida Family AIDS Network have instituted a policy of disclosure by age thirteen, but others have suggested an age as low as ten (Myer et al. 2006) and the American Society of Pediatrics recommends disclosure to “school-age” children, any disclosures occurring at age eleven or older were established as “later disclosures” in this study.

Table 4.5 shows participants’ age at disclosure and their adherence, based on two measures, viral load and recall. Nine of the seventeen participants (53%) learned their diagnosis at the age of 10 or younger, and all of them, with the exception of Keith, were practicing good or excellent adherence. At the time of their interviews, five of the nine (56%) had consecutive undetectable viral loads (see Appendix F).

Table 4.5 Age at Disclosure and Adherence

Name	Age at Interview	Age at Disclosure	Adherence Based on Viral Load	Adherence Based on Recall ¹⁵
Paula	13	<10	U ¹⁶	B
Bridget	18	<10	U ¹⁷	B
Lucy	19	15	U	A
Rachel	16	11	U	A
Valerie	16	<10	U	A
Mark	14	<10	U	A
Nina	17	<10	U	A
Katie	22	<10	Good ¹⁸	D
Vanessa	16	<10	Good	A
Jeff	16	<10	Good	A
Zoë	16	13	Fair ¹⁹	D
Angela	17	12	Fair	A
Stephanie	20	17	Fair	D
Olivia	13	12	Fair ²⁰	A
Diana	19	15	Fair	C
Keith	18	<10	N/A	N/A
Sean	20	16	N/A	N/A

Since this study was limited by the small number of adolescent participants, no statistically-based conclusions between age at disclosure and current adherence level can be drawn. However, it is noteworthy that all but one of the adolescents who learned that they had HIV at a young age were practicing successful adherence, as indicated by consistently undetectable viral loads or periodic undetectable viral loads. The exception was Keith, who had problems with his medications and was prescribed treatment interruption. Conversely, all but one adolescent who learned his or her diagnosis later

¹⁵ Adherence based on recall: A: Never or less than once a month; B: Misses once a month; C: Misses twice a month; D: Misses 3 or more times a month

¹⁶ U: Undetectable Viral Load

¹⁷ Bridget's viral load spiked following her interview.

¹⁸ At least 2 consecutive undetectable viral loads and others under 1500 copies/ml.

¹⁹ Viral loads above 1500 copies/ml

²⁰ Olivia's case may have been affected by viral resistance. Her medication regimen was changed soon after her interview.

were having greater problems maintaining adherence or reaching undetectable viral loads. These exceptions will be addressed at the end of this section.

It should be reiterated that sometimes lower adherence to certain regimens can still result in viral suppression (undetectable viral load), and optimum adherence does not always suppress the virus to undetectable levels. This is because viral suppression and optimum adherence levels also depend on the specifics of the antiretroviral regimen and on the presence of resistance to medications (Maggiolo et al. 2005). As with Keith and Sean, some patients whose treatment has been interrupted can sustain low levels of virus (Noguera et al. 2010; Castro et al. 2010). Nevertheless, high adherence to medications is necessary for viral suppression and low adherence increases the risk of a detectable viral load, that is, the failure to suppress the virus (Martin et al. 2008; Bangsberg 2006) and the risk of viral resistance (Veinot et al. 2006; Quinn et al. 2000).

Profiles: Earlier Disclosure of HIV Diagnosis

The disclosure of HIV diagnosis to children at an early age does not cause excellent adherence, but seems to result in adaptation to both the medical and social challenges of HIV in their lived experience and in a sense of well-being despite these challenges. Adaptation to the disease and a sense of acceptance seemed to foster both an internal fortitude and an external routine that made adherence behavior possible and relatively easy. Short profiles of several of the participants will illustrate the effect of earlier disclosure on later adaptation and adherence. They reveal how accustomed the adolescents had become to HIV as a part of their lives, since early disclosure had made it part of their lives for so long.

Jeff, 16

Jeff is a quiet, polite, 16-year-old tenth-grader. He said he learned of his HIV disease when he was very young, and when asked how he felt about it now, he said, "I'm kind of used to it now. I've been growing into it." He also believed that it was good for children with perinatally acquired HIV to be told about their disease when they're very young, because then "[t]hey can grow into it as a teenager." The early disclosure seemed to make the disease much less disruptive in his life now; as he said, "I don't really think about it. I just live my life as a teenager."

Paula, 13

Paula is extremely forthcoming and knowledgeable about her HIV disease. She is 13 years old, and has known her diagnosis since she was very young. She described her disclosure: "I'm thirteen right now and I don't remember when or who told me. I think I grew up knowing it. I don't remember, I think it was the doctor, but then again, I think it was my father. I don't really remember. But I knew it was for HIV. I knew it was HIV medication I was taking, because my dad left the pill bottle on the counter and when he left, I read it, and it was for treating HIV, and I asked him and he said yes and then, I knew."

Katie, 22

Katie is in her early twenties, and in college. She has lived with her adoptive mother since she was a baby. Her biological mother had problems with drugs, and Katie was taken from her after birth. She had some contact with her biological mother when she was a young child, but it did not continue. She never knew her father. Katie was an

articulate and outgoing woman who was very comfortable talking about her life and her HIV disease, which, as noted above, seemed to be due to the fact that

My mom, she always was open about it. She never sugarcoated, she never hid it from us, and it was never, like, not a discussion or topic...Unfortunately, I know, like, I'd say about four years ago, my mom had gotten a little Spanish girl, and she had just found out when she came to this house, and she was twelve years old. She just found out that she had the virus. And I'm like, she was born with it, and her mother never told her, and I was like, wow, I can't never really imagine that, 'cause I've always known.

Nina, 17

Of the participants who learned of their HIV at a young age, Nina was most plainspoken about the disruption it caused in her life. She admitted that living with HIV was a nuisance:

Well, I felt kind of sad and kind of like...mad because I know it wasn't my fault, it was my mom's fault when she was young, and I understand that and sometimes I kind of like argue with my mom about the situation, because like I got a life that's wonderful but it's still like, I don't know. It don't feel right, like I'm not living the life that everybody else is kind of living, like taking medicines every day and waking up at night...

Yet, Nina has lived with the knowledge of her HIV, and its everyday ramifications, since she was young:

Well I found out when I was a little girl, I don't know what age but I really didn't know nothing about it...The only thing that had told me was that you got to be careful when you grow up with your partner, you gotta tell them your condition and how everything is supposed to be, you have to tell him or tell her that if you do become with somebody you gotta use condoms and if you have a cut you gotta warn the person about the blood, they gotta use gloves or other materials."

Summary: Earlier Disclosure

The adolescents who were disclosed to early all seemed to take their HIV disease in stride. They were a bit more open about their diagnosis with others, though some still

did not think disclosure to friends was a good idea. Most of these adolescents also had a caregiver who was either involved in their care or was accepting of and open about the disease. These two elements of the adolescents' lived experience, awareness of their HIV throughout childhood and caregivers who guided their process of adaptation to the presence of HIV in their lives, resulted in adolescents who were able and willing to adhere well to their antiretroviral therapy. They were also a little more likely to disclose their diagnosis to boyfriends or girlfriends than those who were disclosed to later, though as we saw in the section above, other factors, such as stigma and cultural ideas about secrecy, also influenced disclosure to others.

Profiles: Later Disclosure of HIV Diagnosis

The participants who were disclosed to later seemed less comfortable with their diagnosis and had more difficulty adjusting to or accepting HIV into their lives. They did not seem to understand fully and accept the importance of taking their medications every day, and their adherence reflected this ambivalence. They were also more likely to engage in risky behaviors, such as stopping their medications and having unsafe sex. Finally, there was greater silence surrounding the disease.

Diana, 19

Diana's difficulty managing her illness, at least from a biomedical perspective, has likely been affected by her mother's grave reservations about the biomedical health care that she and daughter have received, as well as her concerns about the efficacy and safety of antiretroviral therapy. However, it is also evident that Diana did not accept and adjust well to her HIV diagnosis when she learned of it at age fifteen, saying "it was kind of a shocker." She had problems with alcohol and drug use after she learned of her HIV,

and as mentioned earlier, she also had unprotected sex. When asked if she thought that the disclosure process could have been done differently, her response reveals that her adjustment was a difficult and confusing time:

“First, I wanted to know, like, I was mad at my mom ’cause she didn’t tell me earlier, but then she explained, like, I wouldn’t know what to do with that information at a young age. So I was like, whatever. But now that I think about it, like, I wish I would’ve known, like, when I turned eighteen or something, you know. ’Cause I know I would have been more mature about it. ’Cause I don’t know, when I found out that just made my life go downhill.”

The delay of disclosure until an individual is an adolescent, such as Diana’s disclosure at age fifteen, means that there is increased risk of unprotected sex and hence possible exposure of HIV to sexual partners and exposure to other sexually transmitted infections for the HIV-infected adolescent before he or she learns of the HIV diagnosis. Though awareness of one’s HIV status does not necessarily mean that one will practice safer sex, disclosure to the adolescent allows for the discussion of the implications of unsafe sex to take place.

Stephanie, 20

Learning her diagnosis at the age of seventeen, Stephanie has had only three years to adjust to this knowledge, years that mark her transition from adolescence to adulthood. Her life before disclosure was marked by secrecy and ambiguity. She lived in her home country until she was fourteen, but she never knew her biological mother. She lived with relatives until her father accepted her as his daughter, at the behest of his wife, Stephanie’s stepmother. She insisted that she did not know she was sick until after she arrived in the United States and was diagnosed while being treated in the hospital for an unidentified illness. At

that time, however, her parents did not share her diagnosis with her, but apparently fabricated an explanation. Finally, at seventeen or eighteen, her doctor disclosed her diagnosis to her. Her reaction differs markedly from some of the participants who learned their diagnosis earlier, before they could be fully aware of the implications:

I didn't want to believe it because they, in my country, I heard when you have that sickness you die. And how am I going to have it. It's none of my parents, it's none of my sister have it, my dad doesn't have it, so I didn't want to believe it... I'm still doesn't want to believe if I was born with it, because if I had it, one of my, my dad would have it, or my mom. Even I, I don't know, because I never know my mom. I don't know if she did have it or didn't have it. I never know my mother.

Learning of her HIV disease at seventeen seems to have been especially disturbing to Stephanie, because she knows little about her history and her family is generally silent about her illness. For Stephanie, this silence is a sign that she is normal, like everyone else in the household. The silence has extended into her social relationships, in which she is unwilling to make her status known to anyone:

...if I have a lot of people at my house, and I have people sleeping over, or if I'm sleeping over at someone house, and that person doesn't know I'm on medicine, and I would not let my friend know I'm on medicine. Because my parents, even at the house, my parents doesn't even mention it. Why would I even try to let my friends know that I'm taking medicine?

She conveyed her fear of stigma, and the extreme caution she would exercise when deciding whom to share her status with:

The person I will spend my life with and I'll know that person would never want to hurt me. I would definitely tell that person. And sometime I think if I ever told them, they might treat me differently because sometime when they talk about people who like, people with other sickness, I saw sometime, I wonder in my head, what if they know I had that kind of disease, how would they treat me. Would they ever be my friend, would they talk to me.

Sean, 20

Sean, like Stephanie, learned his diagnosis at the age of sixteen or seventeen. He had lived with his adoptive mother since the age of seven, and never knew his biological parents. Like most of the participants in this study, Sean was never curious about the medicines he was taking. He explained that it was perhaps because he is “slow” that he did not know why he was going to the doctor and was not told his diagnosis earlier:

I was young and like, I’m kind of like slow, so I didn’t like really catch on till the last minute. I could not understand what AIDS was and all that. I didn’t understand all that.

At 20, Sean was definitely aware of what AIDS was, and he understood the ramifications of sexual activity without disclosure or condoms. His ambivalence about disclosure, both to friends and to sexual partners, was articulated above. He did not share his disclosure with any friends, and said he would not share the disclosure with a romantic partner until he had been with her for two or three years and was sure that it was serious.

Zoë, 16

Zoë was one of the least knowledgeable and engaged participants regarding her HIV disease management. Disclosed to at thirteen, she remembers being angry with her mother for not telling her sooner. Yet, in the three years since disclosure, she has not made an effort to engage in her health care during her clinic appointments, and she has, on at least one occasion, stopped taking her medications for about a month. When asked what made taking the medicines as prescribed a challenge, she gave an answer similar to the reason she gave for stopping them for a month: “Sometimes I have problems, like, going on in my life, or stuff just on my mind.” Though she said she had sole responsibility for taking her medicines, she did not seem to understand the implications

of that responsibility and thus did not seem ready to take that responsibility. Whereas other participants found a way to make room for the medicines, even though it was often problematic and tiresome, Zoë would sometimes just not take them. She is a marked contrast to Jeff and Valerie, both 16, who each expressed some irritation toward their situations. When I asked Jeff, “How often would you say it comes in your mind, I’m so sick of taking these medicines?” he replied, “Like every two days.” Yet, he rated the importance of taking his medicines “really important, like a nine” and said he never forgot to take them. Valerie said that sometimes she still got sad about her situation, both her HIV and her disabilities. When I asked her if, during these times, she ever thought of not taking her medicines, of not “doing this anymore,” she retorted with a laugh, “No, I’m not that upset.”

For Zoe, the integration of her HIV and its management into the ups and downs of her life is still a challenge. As noted elsewhere, she also did not trust her peers enough to reveal her HIV status in those relationships.

Summary: Later Disclosure

The adolescents who learned their HIV diagnosis at sixteen or seventeen were still trying to accept the reality of their HIV three or four years later. Others who were disclosed to later, in their early to mid teens seemed to have accepted the reality of the diagnosis, but their management of the disease appeared to have been undermined by a lack of responsibility, substance use, and other difficulties in their lives.

Exceptions to Disclosure Age -Adherence Correlation

Lucy, 19

Lucy is a curious exception among the adolescents who were successfully practicing adherence, in that she was disclosed to at the late age of fifteen. While it seems that those disclosed to early in life were more comfortable with their diagnosis, more engaged in their health care, and therefore more adherent to their medications, Lucy, too, exhibited this comfort and engagement, and registered undetectable viral loads over the two years previous to her interview. She knew the names of her medications, was aware of their effects on her viral load and CD4 count, referred to them as “my three special friends,” and was the only participant who expressed apprehension about what a rare lapse, in what seems otherwise to be optimum adherence, would mean for her health. As noted earlier, she took her responsibility very seriously, saying, “I got scared ’cause I thought something was going to happen...[t]hat my count would go down really low. Really fast.” She knew that she should never miss even one dose, because “Even if I am undetectable, I want to stay undetectable.” This concern and awareness seems to have served her well, and may be due, in part, to her mother’s role in her life and health care. Anita²¹, Lucy’s mother, has been an AIDS activist and advocate for many years, so the importance of seeking and maintaining treatment, as well as taking responsibility for one’s health, may have been instilled in Lucy even before she knew her own diagnosis. Interestingly, Lucy has a sister who was also perinatally infected, and her engagement and adherence were markedly lower than her sister’s; she has not had undetectable viral loads in a consistent manner. There may be individual psychological, emotional, and

²¹ Pseudonym.

developmental differences that affect the sisters' responses to their HIV and their subsequent success at disease management.

Keith, 18

Keith was one of the participants who learned his HIV diagnosis early, yet he was not successful at adherence. He was also the only one who was disclosed to early who seemed to struggle with acceptance of his diagnosis. One possible variable in his scenario was that he was the only one of four children who was HIV-infected. He talked about this during his interview and even at eighteen, he seemed bothered by the unfairness of it:

My mom had gave us up for adoption, because she was strung out on drugs and she had addiction problem, and she also is infected, and she was the main reason that I really start just like, 'cause when I was young, I was always mad, ever since I found out about it, I just always woke up on the wrong side of the bed and just always taking stuff so hard.

He said that the worst feeling he had about his HIV was, "Well, being the oddball out of your family. That's what I feel like, like a oddball out of the family."

Most of the other participants who were disclosed to early in their lives did not dwell on their HIV when they were young, probably because they did not understand it. Keith, however, seems to have been bothered by his HIV from early on. He talked about being lost and being angry at different points in the interview, and he is still working through it:

[My mother] didn't want me to go through the same thing she went through, so it's kind of like, I didn't go through all the drugs and stuff, but the anger and all, how to release and how to open up to people? Some of that I did go through...

But then,

when I heard about it, I wasn't mad, I was lost, I was lost. So I had to make a way to find that lost image in my head, that I had to register all this stuff about that.

He credits both of his mothers with helping him to work through some of his confusion and anger, and believes that he has made progress.

...like right now today I wouldn't even be talking to you if it wasn't for her [biological mother], because she the one that, her and Debra [adoptive mother] were the ones that opened up to me that I had to let things out to certain, to people, not just certain people, just to people, and let them know how I feel, just so I won't have a lot of stuff build up inside you and all of that stuff. 'Cause it do, it cause you to where you be wanting to do things...

Keith continues to struggle with the unfairness of his HIV disease.

The challenges of acceptance, coupled with medication side effects of nausea and fatigue, led to Keith's discussion with his clinician about continuing to take the medications. The last straw, it seems, was

the new pills they put me on, these horse pills. They'd be so big and my throat, I don't guess my throat got bigger... It's like you got a little knot in your throat somewhere right up in here. And I hate that feeling... Every time I took these pills, I had to get some bread or something thick, to take down, right on top of it... I had to eat a little right then and then I take, and like fill the bottom of my stomach, and then put some more on top of the pills to smother them, just to make sure they was like gone.

Keith said that the clinician directed him to continue taking his medicine until his viral load reached a very low level, and then he stopped the medications. Keith's difficulties with adherence were evident in the months preceding his treatment interruption (see his viral load measures on page 117), so the clinician apparently saw the merit in trying interruption in order to delay the onset of resistance.

Rachel, 16

Rachel is considered a “later disclosure” at age eleven, based on the study’s parameters, but this age is still generally one where sexual activity has not yet begun and is two years earlier than the age for disclosure set by the USF clinic. Thus, this age is difficult to categorize and could be argued to be an earlier disclosure. Rachel learned her diagnosis at age eleven, because her best friend’s father told his daughter not to share drinks and straws with Rachel, because she had HIV. Once her friend knew, Rachel’s mother knew that she had to tell her daughter the truth. It was not allergies, as she had been told for years, it was HIV. Rachel said that she must have known something was not right about the allergy explanation, because she was taking around twenty pills a day at the time. As with the others who were disclosed to earlier, Rachel did not really understand HIV so it did not occupy her thinking. She, like the others, grew up with it, and added to her understanding and acceptance as she matured. The evolution of her thinking is evident in the following, and shows how her situation at 16 is very different from, say, Zoe, who is 16, or Stephanie, who did not learn her diagnosis until she was 17:

Well, I would have to say that when I first found out and throughout middle school, I just kind of put it out of my mind. It wasn’t a problem for me and I just kind of forgot about it. I still knew that I had HIV but I just kind of let go of it, like, whatever. But as I’ve gotten older, I guess I have thought about it more, and just like I’ve gotten more opinionated about life, and I guess it’s kind of like now that I’ve matured and gotten older, I’ve gotten a better sense of how I look at life, and I don’t look at my HIV as a bad thing. I look at it that I was put here for a purpose and I’m going to help out the world with what I know, and that’s been a pretty recent thing for me, because I would have to say like last year, tenth grade, I really started to get into like being HIV positive...I was like, you know what, this is a part of me and I need to take advantage of that, so I have, I guess. It hasn’t really happened until this year but that’s what I decided the last year, if that makes sense.

Of particular significance and, it seems, benefit was Rachel's recent attendance at national AIDS conferences, where she learned about others' experiences of living with HIV openly and without shame or fear, and about being an HIV advocate and activist. Her profile reflects the conflation of her own dislike of lying to others in order to hide her HIV and becoming a person who does not have to.

Challenges of Disclosure: Biological Mothers

Disclosure of HIV status to a perinatally infected child is a highly charged issue, and the pain, guilt, and shame that accompany the disclosure can be particularly acute for the biological mother. Studies show that disclosure tends to be later or is desired to be later among biological mothers (Wiener et al. 2007; Ledlie 1999). In this study, a focus group was conducted with a group of biological mothers of infected children to explore the issues of adherence, health care, and disclosure from the mothers' perspective. It was hypothesized that the mothers' attitudes and behavior regarding their own and their children's disease management would influence how the children adapted to and experienced HIV in their lives. Included in their attitudes toward disease management were their ideas about the best time to disclose the HIV diagnosis to their children.

Six mothers assembled for the focus group. Four of the mothers in the group had children in the study. Five women were the mothers of infected adolescents, and one was the mother of an infected six-year-old child. Table 4.6 shows their children's ages at disclosure, along with the mothers' demographic characteristics. Most of these mothers disclosed the HIV diagnosis to their children at a later age.

Table 4.6 Biological Mothers in Focus Group

Mother's Name	Age	Race/Ethnicity	Age of Child at Disclosure	Number of Infected Children	Uninfected Children
Rita	41	White	11	1	No
Donna	53	Black	15	1	No
Anita	47	Black	12 & 15	>1	Yes
Joyce	48	Black	9	>1	Yes
Teresa	44	Black	Not disclosed ²²	1	Yes
Nancy	43	Hispanic	11	1	No

The women were mostly in agreement that young children should not be told they had HIV, because they would not understand what HIV was or its implications. They also mentioned trying to preserve their children's childhood and a sense of normalcy by not disclosing their diagnosis to them. There was concern about the children telling others indiscriminately and also worry about what the children would think of their mothers. Because most perinatally infected children take antiretroviral medications from an early age, the mothers kept the truth from their children by giving vague explanations or lying about why they had to take the medications. Rita voiced her reservations about disclosing to very young children this way:

...when we found out, it was, we had "allergies" and we took "allergy" medicine and we kind of have to give it to the kids as they understand it, because I'm sorry, a five-year-old is not going to understand, I'm sorry, they're not going to understand what it means, and I'm sorry, an eight-year-old is not going to understand. Maybe a ten-year-old, I doubt it, so you know, you just have to, you have to go slow.

Anita told her children when they were 12 and 15, but wished that she had told them earlier, before adolescence:

²² Teresa's infected child was six years old.

With my kids, I wish that I would have told them, started talking to them about it at younger ages, so that they can understand and because it was like I dropped a bomb on them when I told them, and being a adolescent, I really feel bad about that, and I wish I, if I could go back and do it differently I would, because it interrupted their whole life. "I'm a teenager, I have friends, I'm looking at dating, you know, and now you just told me that everything has to be different," and if I would've went ahead and just told them, and just started educating them at a young age, so that as they grow, they can grow into understanding the virus, it wouldn't have disrupted their life as much.

Anita also admitted that her delay in telling her children was a reflection of her own fears:

But my own fear stopped me from doing what I needed to do as a mom and as a parent, 'cause I was so scared that, oh, they're going to think I'm a horrible person, oh, they're not going to love me anymore, those were the things that was going through my head.

Donna talked at length about being pushed to disclose to her daughter when her daughter was very young and also when she was a teenager, the age at which Donna finally told her. She expressed the feeling of not being allowed to control her and her daughter's lives, especially by health care providers, and conveyed a great deal of resentment at the attempts by the health care system to ignore her own knowledge of HIV and ability to take care of her daughter:

I said, what is she going to do with that information. She's four years old at the time or three years old, you know...what is she going to do with that information. "Oh, now, mommy, now that I know, I'm going to start taking better care of myself?" Or is she going to go and, or if I tell her, don't tell anybody, you know, she's going to start having a self-esteem [problem], you know, or is she going to tell people and people are going to, 'cause at that time, you know, right now it's not as bad as it was. And you know, they would just [say] I was doing her such an injustice by not telling her...So I had a lot of doctors who pushed me into telling her, and I says, I have to tell her when I feel that I'm ready. I'm the one that's going to have to deal with this, and when I feel that she's ready...But...they kind of forced my hand a little bit, and it's rough how they play these games, but, so, you know, I was forced to tell her when I was unprepared. I knew she wasn't, the therapist said that she wasn't prepared...

Teresa, whose infected child is six, also had reservations about disclosure. She believed her son was too young, and if told at this age, he would “go to school and say, hey, guess what I have, and I know how he is, I know how he’s so energetic. He is so energetic, and he’s like, everything you basically tell him, he’ll just go and run it, run with it.” However, she did not feel comfortable with the idea of disclosure when he reached the age of thirteen, the age by which the clinic had determined that all children be told. She worries about the effect it will have on a young adolescent, because “it’s like, you tell him at the age of thirteen, that’s knocking them down, at the age of thirteen, ‘cause that just getting to know who, trying to get to know who they are, and then they got friends.”

Anita brought up difficulties that perinatally infected children and adolescents may have with adherence upon learning their HIV diagnosis. Since most of the children will have been taking antiretroviral medicines before they learn their diagnosis, the reaction to the disclosure may have a negative impact on how the child manages his or her disease henceforth. Anita said that this was why she thought disclosing to her children at a younger age would have been beneficial:

I felt like I should have told them when they were maybe, start talking to them about it, when they were seven or eight, nine years old, so that they can get an understanding and grow into it...My daughter was doing great in school. She had no problem with taking her meds. Every day she took them. But as soon as I told her that, “I don’t want to take them. I don’t like it, it makes me sick, it’s nasty, I can’t swallow it,” hiding pills, you know, I mean, the dog eating the pills, getting sick. It was just a whole process that, and it was worse than what it could’ve been if I just would’ve opened up.”

The same reservations are implied among the group of adolescents in this study. Nine were disclosed to by their biological mothers, and eight by other caregivers.

Though this is a small sample, it is interesting that the biological mothers were more likely to disclose later than the other caregivers were, which is in line with the literature.

Table 4.7 shows the study adolescents by age at disclosure and caregiver making the disclosure.

Table 4.7 Study Participants' Disclosure by Caregiver

Name	Age at Disclosure	Disclosed to by
Paula	<10	Biological Father
Valerie	<10	Biological Mother
Mark	<10	Biological Mother
Nina	<10	Biological Mother
Katie	<10	Adoptive Mother
Vanessa	<10	Does Not Remember
Jeff	<10	Biological Father
Bridget	<10	Adoptive Mother
Keith	<10	Biological Mother
Rachel	11	Biological Mother
Olivia	12	Adoptive Mother
Angela	12	Biological Mother
Zoë	13	Biological Mother
Lucy	15	Biological Mother
Diana	15	Biological Mother
Sean	16	Adoptive Mother
Stephanie	17	Doctor

Of the biological mothers who disclosed to the adolescents in this study, four out of nine disclosed earlier, that is, to children under the age of ten, while five mothers disclosed later to their children. Conversely, of the eight other caregivers, including biological fathers (ostensibly all HIV-negative in these cases), five disclosed earlier and three disclosed later (or not at all, in the case of Stephanie). Table 4.8 summarizes these numbers.

Table 4.8 Early and Late Disclosure by Caregiver

	Disclosed Early	Disclosed Late
Biological Mothers	44%	56%
Other Caregivers	62.5%	37.5%

The focus group discussion, as well as the age at which the study participants were disclosed to by biological mothers, illustrates the serious reservations and anxiety that biological mothers have about naming their child's disease early in the child's life. Not only were they concerned about their children's capacity to cope with the diagnosis at a young age, but they might also be plagued by their own fears about how their children would regard them. After all, the child's disclosure in this case is also the disclosure of the mother's HIV status.

Summary of Findings for Hypothesis 3

The results demonstrate the merits of early disclosure of their diagnosis to children perinatally infected with HIV. Though there are many other factors affecting the adherence success of these adolescents, early disclosure seems to be a powerful factor in promoting the adaptation of the children to their disease, the consequent understanding that occurs early in their lives, and the ability to integrate the medications into their daily routines. However, the difficulties of disclosing the HIV diagnosis to a young child, especially by biological mothers, cannot be overlooked.

Health Status and Adherence: The Illness Role in Chronic Disease (Hypothesis 4)

For an adolescent dealing with HIV disease since birth, the management of the disease can become tiresome. Adolescents trying to be more independent may decide

that they do not want to continue taking their medicines, or at least desire a temporary reprieve. If long periods of good health are experienced, adolescents may become complacent and this could lead to poorer adherence. The fourth hypothesis addressed these issues:

Health status has an influence on an adolescent's adherence. Very healthy or very ill individuals are more likely to stop taking their medicine, or to take it sporadically.

The participants in the study were all healthy at the time of their interviews, and none had had any serious illness episodes or hospitalizations in the recent past. When asked if they were ever sick or in the hospital, most said that they remembered such incidents, some quite serious, when they were young children, but as adolescents none had any serious illnesses in the last several years. All were healthy, yet some were optimally adherent, while others had trouble with adherence. None voiced the idea that it seemed unnecessary to take medicines because they were healthy; all knew that taking their medicines every day was necessary to maintain their health. As we have seen above, other factors, such as psychosocial problems, lack of support, and inconvenience, led to problems with adherence. While there were no adolescents who were currently seriously ill, those that did describe past illness episodes did not say they stopped taking their medicines. In fact, the illness was more the result of having stopped taking the medicines, and spurred them to resume taking them.

Sean was the only participant who may not have fully understood the necessity of taking the medications even when one was healthy. His explanation of why he had stopped his medications contained no mention of difficulties with taking them or maintaining adherence, which was the reason his clinical provider advised the

interruption. Sean saw it this way: “I was doing good and they wanted to see if I could keep doing good off so they just gave me the chance to stop and they said I was doing good without it.” His problems with adherence may have been due to his thinking that he was healthy and didn’t need the medicines, but Sean had other problems, including serving time in jail, not knowing his biological family, and not understanding and accepting his HIV since his late disclosure at about the age of sixteen. These psychosocial issues may have thwarted his efforts to adhere to his medications.

While this hypothesis could not be tested in this sample of adolescents, it does raise a related issue, that of understanding the medical implications of HIV and its management now that the disease is experienced as a chronic condition. Some of the participants iterated the importance of the medications to maintain their health and keep their viral loads undetectable, and this indicated an understanding of treatment even during long periods of good health. However, most of the adolescents did not have a thorough comprehension of the implications of sporadic adherence on their future health outcomes and medication options, nor did they express the importance of low viral loads in reducing the risk of transmission to sexual partners. There may have been some level of carelessness or lack of vigilance as the medications have become more effective, less cumbersome and harsh, and therefore, more routine. The exact blend of routine behavior and serious vigilance, and its effect on successful disease management, is an issue for further study and implementation in HIV education and counseling.

Summary of Results

The data show that the active engagement of adolescents in their HIV disease management (Hypothesis 1), the openness about and involvement in HIV disease

management of the caregiver (Hypothesis 2), and earlier disclosure to the infected child of his or her HIV diagnosis (Hypothesis 3) seemed to be associated with the adolescents' better adjustment to the vicissitudes of disease management, especially adherence to medications. Secrecy, shame, and stigma were underlying negative factors in the adolescents' ability and willingness to share their diagnosis with peers and sexual partners, and to practice optimum adherence.

Biological mothers, other caregivers, and health care providers had an influence on how the adolescents accepted and integrated information about their disease into their lives. Biological mothers were more reticent about disclosing the HIV diagnosis to young children, but their faith in the importance and effectiveness of antiretroviral therapy seemed to have a greater impact on their children's adherence than their own adherence to medications did. Other caregivers were a bit more likely to disclose the HIV diagnosis to children at a younger age than biological mothers were. The current stability of the family and their adaptation to HIV appeared to have a greater influence on the children's disease management than did past instability and loss of parents to HIV.

The rating of the patient-provider relationship did not differ considerably between adolescents with optimum adherence and those with only fair adherence, though the adolescents with the most adherence problems did rate this relationship lower than the other adolescents did. The interviews with adolescents and clinicians did reveal, however, that adolescents construed the communication and interaction styles of providers differently from the way that providers described them. Among the providers themselves, the styles were quite variable, though the impact of any individual style on a patient's disease management and health outcomes was not explored in this study.

Overall, the adolescents had only a basic understanding of the medical aspects of HIV, including the effects of adherence, the ramifications of non-adherence, the meaning of HIV-related lab measures, such as viral load and CD4 count, and the meaning and implications of viral resistance to antiretroviral drugs. The less they knew and were invested in the importance of their disease management behaviors, the less consistent they seemed to be in their medication adherence.

Most of the adolescents were extremely reticent about sharing their HIV status with peers, and of those who were sexually active, disclosure and use of condoms was not practiced every time.

The implications of these results, for perinatally infected adolescents and their families, as well as for the clinical and social service providers who are part of the Florida Family AIDS Network, will be discussed in the next two chapters.

CHAPTER 5: DISCUSSION

Successful management of human immunodeficiency virus (HIV) disease is directly linked to optimum adherence to one's antiretroviral drug regimen. The development and availability of different classes of antiretroviral drugs, as well as prescribed therapy that usually involves several different drugs taken in combination, have transformed this disease into a chronic, manageable condition. The possibility of long-term survival and improved, stable health outcomes, however, depends on rigorous adherence practice. The level of adherence to therapy also affects the continued sensitivity of the virus to the drugs, that is, the likelihood of viral resistance to the drugs.

HIV disease management also has public health implications insofar as it involves the prevention of virus transmission to others, most often through sexual activity. The risk of sexual transmission of HIV is particularly affected by sexual practices, and also by the viral load, or the number of copies of HIV per milliliter of blood (Quinn et al. 2000). Sexual behavior and viral loads represent the many social and medical aspects of HIV disease management, aspects which interact with each other and demand a comprehensive examination. At the same time, disease management is an individual endeavor, with individual variations, so a focused, qualitative analysis holds promise of addressing and elucidating the personal, social, cultural, and medical constituents of this particular group's HIV disease management (Sankar et al. 2006; Collingridge and Gantt 2008).

HIV disease management owes its complexity not just to its individual and public health effects, but also to the indirect or more distal factors that complicate its execution. These factors are numerous, diverse, and complex. The preceding chapters have been an attempt to present some of these factors from the perspective of adolescents with perinatally acquired HIV disease. In this chapter, I will discuss perinatally infected adolescents' experience with adherence to antiretroviral therapy, the mainstay of HIV disease management, and the significance of the disclosure process in sustaining successful management of HIV from childhood into adolescence and young adulthood. The discussion will be embedded in the medical ecological framework, in which "health and disease...are informed by the perceptions and social relations of patient, healer, family, and community...[and] [i]nsults can originate from organic, inorganic, and all aspects of the cultural environment" (Armelagos et al. 1990:358).

The major themes to emerge from the findings of this research provide support for the medical ecological perspective on the chronic disease experience, and for the saliency of spheres of social, cultural, and medical influence which make up the adolescent's lifeworld. These themes include the factors that most significantly associated with the adolescents' adherence to therapy and overall HIV disease management. They are:

- 1) early disclosure of HIV diagnosis and caregiver attitudes and support
- 2) the dominance of HIV disease as a socially-felt affliction over a medically-experienced condition
- 3) the chronic illness identity and experience
- 4) the process and meaning of disclosure to friends

- 5) biomedical knowledge and understanding of HIV and its personal and public health implications
- 6) stigma as the underlying theme

Each of these themes will be discussed, followed by sections on additional issues related to adherence that were not addressed in this study and unexpected findings among the adolescents that did not support the hypotheses.

Themes

Disclosure of the HIV Diagnosis to the Child and Caregiver Attitudes

A child with perinatally acquired HIV cannot really begin “growing up” with and managing HIV until he or she knows the name of the “bug in your blood” or “the bad guys in the blood,” as the clinicians described HIV to their younger patients. Naming the bug begins the process of owning their disease and gaining control over it. Eight of the nine participants in this study who were told they had HIV when they were young children, age 10 or younger, were either optimally adherent to their medications, as evidenced by consistently undetectable viral loads, or were practicing good adherence, with alternating undetectable and low viral loads. Only one adolescent who was disclosed to early had problems taking his medicines and was taken off the medications in order to prevent the development of resistance. Conversely, among the eight adolescents who were disclosed to later, at age 11 or older, all but two had detectable and markedly fluctuating viral loads, indicating some problems with adherence.

Findings from studies that looked at psychological and emotional issues following disclosure have been inconsistent, though some positive effects of disclosure have been found (Butler et al. 2009). Among my study participants, the most positive effect, that is,

successful adaptation to HIV in their lives, seems to be affected not just by disclosure, but by early disclosure. While no tools to measure quality of life indicators were used in this study, the interviews reflected more acceptance of their status among those disclosed to earlier and excellent or very good adherence behavior. These adolescents grew up knowing about their HIV even before they fully understood it, whereas those who learned the diagnosis later, already knew about HIV (and likely were aware of its negative connotations) and experienced distress and dismay. As with adults who are diagnosed with a chronic illness, adolescents who learn their HIV diagnosis later in adolescence seem to experience the diagnosis as a “biographical disruption” (Bury 1982), whereas those disclosed to earlier adapted early to the knowledge and to the disease with little disruption.

Diana, disclosed to at age 15, said it was “a shocker” and was angry with her mother, and then she said her life went “downhill.” Sean, who learned his diagnosis at about 16, was “really, really sad” and still, after a few years, says, “it still get to me, I still be hurt. I still be hurt that I got it.” Stephanie said, “I didn’t want to believe it” when the doctor told her, at age 17, that she had HIV. Valerie, on the other hand, “wasn’t really sad or anything,” when she learned about her HIV at age seven or eight. Jeff, age 16, said, “I’m kind of used to it now. I’ve been growing into it,” having known his diagnosis since he was five or six. Mark expressed the advantage of early disclosure: “I didn’t really know what it was at the time so I didn’t really get all dramatic about it.” All of the adolescents who learned their diagnosis earlier seem to have accepted it into their lives. Only Nina expressed some wistfulness when she said, “I got a life that’s wonderful but...

I'm not living the life that everybody else is kind of living, like taking medicines every day.”

The adaptation of the participants who were disclosed to earlier also seems to have been influenced by their caregivers' attitude to HIV. As one of the clinicians had argued, the patients who had the fewest problems with adherence were those who had not just loving, stable families, but open families. The caregivers or parents (three of whom were in the mothers' focus group and two of whom had some input at the time of their child's interview) of half of the study participants who were disclosed to earlier and managed their disease better generally did not treat HIV as a secret, nor were they ashamed of it. The caregivers of the other participants who were disclosed to earlier did not have input in the study, but all except Keith were adjusted to HIV in their lives and did not convey any discomfort in their discourse. Lucy's mother was involved in HIV advocacy and very open about her HIV, and this may have had an impact on Lucy, who, despite being disclosed to quite late, was nonetheless very adherent and made room for her medicines in the routine of her everyday life. Parents who delay disclosure, on the other hand, may have their own problems coping with their diagnosis (Wilfert et al. 1999), and so are not ready to face the inevitable explanations that will come with disclosure to their children (Lester et al. 2002; Ledlie 1999). The openness of the family about HIV means that there is greater acceptance and less shame about HIV, and this may be a key factor in preventing the child's developing and harboring a sense of shame about his or her own HIV.

Conducting the research from the perspective of medical ecology situated the adolescents in the social and medical contexts in which they experience their HIV, and

highlighted the family context as the setting for health practice (Novilla et al. 2006). It was clear that the families and primary caregivers of the adolescent participants had an influence on the social and medical aspects of HIV – the meanings of HIV adopted by the adolescents, their adjustment to and engagement in HIV disease management, and their adherence to medications and other health-related behaviors. The parents or other caregivers who approach HIV without fear or shame, and discuss it openly with their children, afford these children with the opportunity to learn, accept, and engage in their HIV care. These caregivers are also apt to disclose the diagnosis earlier in the child's life. Studies have shown that good adherence is highly correlated to complete disclosure to the child by his or her caregiver (Shet and Kumarasamy 2008; Bikaako-Kajura et al. 2006).

The accommodation of HIV into the family dynamic is often a complicated process. In particular, families with an HIV-infected child who are headed by the biological mother or parents necessarily have two or more HIV-infected members, and often also uninfected members. The disclosure process itself can be wrought with anxiety, raising questions about how and when to disclose each person's status. In this research study, two participants in the mothers' focus group were known to have both infected and uninfected children. One mother revealed the difficulty she had in accepting her own HIV, her fear of disclosure to her children, and her conclusion in retrospect that earlier disclosure to her children would have been better for them. The other mother in the group admitted that she had not disclosed her and her youngest child's HIV status to her four older children.

The attitudes of biological mothers toward their own HIV disease, their adherence to medications, and their health care also may have effects on how their children face their own disease and its management (Cunningham et al. 2006). We have seen that Donna, one of the mothers in the focus group, opposed much about the biomedical system of care and was extremely dissatisfied with the interactions she experienced with biomedical practitioners. There is some evidence that beliefs about biomedical health care and the quality of the patient-provider relationship have an impact on patients' health outcomes, adherence to medications, and retention in health care (Beer et al. 2009; Beach et al. 2006). Indeed, Donna did not take antiretroviral drugs, and used herbal medicine instead. She did intimate that her daughter was continuing her antiretroviral therapy, but was not happy about the prospect of her daughter's continuing these medications indefinitely (Shah 2007). Another mother, Teresa, was not very adherent to her own medication regimen, but was very attentive to her child's adherence. If the mother embraced the efficacy of antiretroviral medications, she was more apt to assist her child in adherence behavior, though she herself might not be very adherent.

Caregivers and parents need support, both in their own adjustment and in guiding their child's HIV management (Steele et al. 2007). Disclosure to children sometimes requires a team effort of the caregiver and clinical network (Waugh 2003; Gerson et al. 2001), as the clinicians in this study explained, and biological and unrelated caregivers alike need to be instructed on and understand the clinical implications of adherence and non-adherence to medications. In addition, the responsibility for children's medications must be well delineated (Marhefka et al. 2008; Martin et al. 2007), so that there is no confusion about who in the household needs to remember each dose. Assistance from

another adult may also help caregivers in ensuring optimum adherence in the child (Reddington 2000).

The findings from this study also showed that the openness of the family or caregivers about HIV and their serious involvement in their children's HIV treatment are key elements in the successful adherence of the adolescents. It did not matter whether the caregiver was a biological mother or adoptive mother, whether the adolescents had lost parents to HIV, or if they were born into unstable situations. What mattered was the active involvement of the caregiver and the acceptance of HIV as a part of their lives.

Approaching HIV disclosure early in the child's life allows the caregivers to begin a gradual process of increasingly detailed, age-appropriate explanations (Lipson 93), so that by the age of 10 or 11, the child has been adequately prepared to understand and accept the HIV diagnosis. This process, followed by early disclosure, allows for a longer period of living with the knowledge, so that by the time the children reach puberty, are developing their identity, and are exploring their sexuality, HIV has become more habit than hang-up in their lived experience.

In one study, health care providers favored six years of age for the commencement of health discussions, because children can understand basic concepts of health and disease, and age ten for introducing HIV into the discussions, an age when more complicated explanations are possible (Myer et al. 2006). The reticence of parents and other caregivers, however, to disclose to the child early has been shown in my study and in others to be due to their belief that children cannot understand and handle the information, but also because the disclosure of a child's HIV necessarily exposes the family's HIV history and the sometimes difficult circumstances surrounding its

contraction (Lesch et al. 2007; Wiener et al. 2007). The child's vulnerability to difficult truths, as well as the experience of health and illness, are socially constructed notions (Christensen 2000) that, in some families, relegate the child to a silent and dependent status, rather than acknowledge the competency and awareness that children demonstrate as social actors in their own right (Prout 2000).

It is this legacy of shame, guilt, and secrecy that differentiates perinatal HIV from other childhood illnesses (Wiener et al. 2007; Lester et al. 2002; Lipson 1994), and makes disclosure of HIV to a child an experience wrought with psychosocial challenges. However, the capacity of the child to accept and understand his illness has been studied and recognized in the cases of other childhood illnesses (Lester et al. 2002; Bibace and Walsh 1980), and there is no reason, barring individual social and developmental contingencies, to think that children with HIV cannot do the same, as my study has shown. In fact, this research study was approached from the perspective of the adolescent (and the young child) as a capable social actor experiencing HIV in a culture of adolescence that is separate from the culture of adults. Because many perinatally infected individuals are now living with HIV well into their twenties, the necessity of learning about, accepting, and preparing to manage their HIV must be considered not only an individual and public health need, but also a right (Corbin 2008; Lesch et al. 2007; Pfaff 2004) that it is incumbent upon the adult culture – parents, teachers, health care providers – to respect and grant.

Equipping children and adolescents with knowledge is a key ingredient in their development of power over their disease and thus over their disease management (Fisher et al. 2006). Especially for the perinatally infected, this feeling of power is crucial,

because they have had no control over getting the disease and they also may have lost a parent or sibling to HIV, which may leave them feeling powerless and hopeless about their own futures (Steele et al. 2007). One of the ways to begin this process of empowerment is instructing young children about how to take their pills and clearly delineating the roles and responsibilities of child and caregiver (Marhefka et al. 2008). Katie, who was disclosed to very early in her life, nonetheless, did not take full responsibility for her medicines until she was eighteen. She believed that beginning the process at about the age of eight, and teaching children about dosage and showing them how to read labels, would make remembering to take the medicines and assuming full responsibility much easier as they grew into adolescence and adulthood. She said,

...if I would have started when I was maybe like eight years old, when I really grasped the understanding about it, it would have been a lot easier... [L]ittle kids aren't going to understand everything, but you teach them or tell them what they're capable of understanding and then they get kind of used to it.

Now that children have a very good chance at an extended future, this cultivation of power, which seems to have been taken from them right at birth, is an even more urgent need for maintaining their health and protecting their sexual partners. It is also important for these children to begin the process of accepting and gaining power over their HIV, because the sting of social stigma that they will inevitably face, even if it is just listening to others talk about AIDS, as the study participants shared, may be lessened if they have been cultivating a sense of strength and acceptance about their HIV from early in their lives.

We have seen that HIV management is sometimes an annoyance, and adolescents especially want to be independent, in control, and perceived as normal. All of the

participants expressed negative aspects of having HIV, whether disclosed to early or late. Vanessa mentioned the hassle of medication and Lucy said she wondered about the possible progression of her disease. However, about two-thirds of the adolescents remarked on the difficulties that HIV could cause in social interactions, and this makes it all the more critical that they begin to deal with these issues before they become involved in social relationships. It is for this reason that the American Academy of Pediatrics (Wilfert et al. 1999) suggests disclosing to school-age children. Social interaction at young ages, for example, requires that HIV-positive children be aware of the danger of blood should they get hurt. However, for adolescents, including this study's participants, social interaction at older ages involves establishing trust with peers and becoming sexually active, and HIV can complicate these developments.

Dominance of HIV as Social Phenomenon

The disclosure of the HIV diagnosis to children or adolescents transforms the “unknown secret” of their HIV status into HIV as reality (Mellins et al. 2002:112). How they make sense of this information, that is, the meanings they construct for their disease, depend on the dynamic social and cultural contexts of their lived experience (Fife 1994: 315; Thorne 1999:400). For HIV and AIDS, these contexts include stigma, shame, and secrecy, which become more or less salient as the child ages and his or her social world changes. His or her cultural values and interactions will also dictate whether and to what degree these aspects become a part of the child or adolescent's HIV experience. As Zoë and Sean made clear, sharing their status with romantic partners was not an option at present, and even Paula, who was quite comfortable with her status, categorically denied it when confronted by school mates because she was knowledgeable about HIV/AIDS.

The participants in this research study embraced both social and medical meanings of their HIV, though the interviews revealed that they highlighted the “social course” of the disease and the “social experience” of HIV in their lives (Kleinman et al. 1995:1323, 1325). All but one of the adolescents in this study spoke much more about the social ramifications of HIV than the medical effects. Lucy was the only participant who brought up the medical aspects more than the social effects. She brought up the issues of taking or forgetting her medicine, of wanting to remain undetectable, and of thinking, “do I want to live to see another day. So I stop and I drop everything I’m doing and take it.” Virtually all of the others pointed out the difficulties of telling other people, including romantic partners, the reactions of others who learn about their diagnosis, the ignorance of others about HIV, and the stigmatizing reactions of people who learned their diagnosis.

Even though Lucy was disclosed to late and had constructed the most salient medical meaning of HIV disease, in general, it was the adolescents who were disclosed to early in their lives who saw the disease in somewhat more medical terms (in addition to social terms) than did their late-disclosed counterparts. They knew a little more about their medicines, about their lab tests, and were more adherent to their medicines. Those disclosed to later experienced their HIV and defined it in more emotional terms and by its effects on their social interactions. For some, like Zoe, Diana, Angela, and Stephanie, there was a sense of denial or separation from the disease, as evidenced by stopping their medications and preferring to ignore the disease in family and peer interactions. Whereas the adolescents disclosed to early experienced control of their disease through acceptance and adherence, the others took control by opposite tactics, denial and refusal.

The medical versus social meaning of HIV has implications for whether and how much these adolescents exercise agency in their experience and management of HIV. Those who adopted a medical, in addition to a social, meaning of HIV understood, to a greater degree than those who did not, the clinical aspects of the disease, the effects of medication and medication adherence, and the importance of assuming responsibility for beneficial health-related behaviors. It appears that the participants who were disclosed to early adopted this more medical perspective of HIV before the experiences of adolescence – social and developmental complexities, such as the formation of the adult self and identity, exploration of one’s sexuality, and the onset of romantic and sexual relationships – began. While social meanings of HIV were constructed by all of the adolescents, if HIV as medical construct anteceded or coincided with the social meaning, it seemed to provide the adolescents with a foundation to support their ongoing involvement and engagement in their health care and treatment (Gerson et al. 2001). It may also affect how these adolescents approach the social and cultural attitudes and meanings that they face and develop later in life, since they have approached the disease first as a medical reality and subsequently or coincidentally as a social one.

Attaching a medical meaning to HIV and engaging early in HIV care and treatment may aid in the child’s development of an adolescent and adult identity that affords rather than denies a space for HIV. These adolescents are then likely to exhibit problem-centered coping (LeBlanc et al 2003), having reached an acceptance of their HIV as a part of their developing selves (Hosek et al. 2002). Those who learn of their HIV as older children or as adolescents appear to use a more emotion-based strategy (LeBlanc et al 2003), which has been shown among the study participants to result in

denial or avoidance, reactions that can have negative consequences on both physical and mental health (Dahlbeck and Lightsey 2008).

It is notable that one of this study's clinician interviewees emphasized the danger in an adolescent's adopting a disease identity:

So with an adolescent you don't want them to develop a disease identity but you want to empower them to learn to fight it. So sometimes you've got to let them go to the rocky times as you're working towards, you know, let them separate themselves from the disease and that's what they're doing when these perinatal kids stop taking the medication. [Ed]

In the next sentence, however, he acknowledged the detriment involved in this kind of behavior: "They're trying to separate themselves from the disease and you don't want that, because then they become really awful adult patients." The psychological underpinnings of adolescent identity formation are beyond the purview of this analysis, but from an anthropological perspective, there is room for the child and, later, the adolescent to engage in positive symbolic interactions with the immediate actors in his or her medical ecological niche – peers, family, community, and health care providers. These interactions, especially when initiated early in the child's life, can produce new meanings of HIV that contest the "flawed identity" (Hosek et al. 2002:356) engendered by social stigma. Among the study participants, those who learned their diagnosis early and had caregivers who normalized the child's condition succeeded in incorporating their HIV and its treatment into their developing selves and "reframing...the ontology of suffering" (Kleinman et al. 1995:1321).

The meanings construed and identities realized gradually throughout these children's lives work in tandem to influence the agency they exercise in the management of their HIV. I have argued that a precedent medical meaning, developed early in the

child's life, accompanied by the development of a normalized illness identity, produce a more engaged individual, whose agency, the "socioculturally mediated capacity to act" (Ahearn 2001:112), results in consistent behavior, feelings of power, and responsibility. The age at disclosure, parental attitudes and beliefs, the role given to stigma in "creating sickness stories" (Kleinman et al. 1995:1321), the medical efforts to engage children, to name the most important factors, have an impact on whether an adolescent has the capacity to take control of his or her disease and be an active collaborator in his or her treatment and care.

HIV as Chronic Disease: Meaning, Identity, and Agency

Adolescence is a stage during which individuals want to fit in, feel normal, and exert a measure of independence. The presence of HIV threatens all three of these objectives. Accommodation to the rigors of health care and medication adherence does not mean that these young people do not grow weary of the constant reminders and inconvenience of their illness (Belzer et al. 1999). Health care and medication fatigue are a danger among these adolescents, and as we have seen, they sometimes decide to stop taking their medications (Pontali 2005). The early disclosure of HIV holds the promise of the child's gaining a sense of normalcy about HIV early on, and certainly by the time they reach adolescence. The earlier the explanation of HIV and its treatment begins, the sooner the child can begin to take control of the condition and its ongoing exigencies, thereby facilitating habituation. The more habitual the HIV care and treatment become, the less it will interfere with the normal adolescent culture that he or she shares with peers. HIV must remain an important part of the child or adolescent's experience, but at

the same time, the familiarity with and proficiency at the daily health-related behaviors make it less prominent in that lived experience.

Disease management, especially adherence, is a challenging endeavor for all perinatally infected adolescents, even those who learned their diagnosis early. It presupposes a measure of control and skill. The adolescent's opportunities to gain control and skill, and then to apply that control and skill to addressing the medical needs of his or her HIV disease, are limited by the medical, social, and cultural resources, that is, the medical ecology in which his or her lived experience is situated (Armelagos et al. 1990). These resources are embedded in concentric circles of socioecological influence (Steele et al. 2007:59). The perinatally infected child is surrounded first by family, some of whom may also be living with HIV or may have died as a result of it. Beyond the family, he or she has interaction with friends, school mates, teachers, neighbors, and others in the immediate community. The next influential niche is the health care system and the practitioners who care for the child or adolescent (Steele et al. 2007).

The capacity to act is a phenomenon that the above social actors around them have been ambivalent about facilitating or accepting in the perinatally infected adolescents, and they have at times had a negative influence on whether or how these young people act in the face of HIV (Pontali 2005). Diana's mother, for example, insisted on preparing her daughter's medications, even though Diana was 19, but at the same time harbored negative feelings about the safety and efficacy of the medications. Others in the adolescent's environment may either promote agency based on secrecy, shame, and difficulty in accepting the disease as normal, or they fail to allow them agency at all. Their peers have been shown to be especially influential in this regard.

More than one of the participants pointed out the ignorant or mocking comments from school mates. The medical ecological environment is not always a sympathetic one, from the family members who demand secrecy, to the peer network that mocks and excludes, to the social community that stigmatizes, to the health care practitioners who are both reproachful and overprotective. Among the adolescents in this study, we have evidence of each of these pitfalls or lack of support to successful disease management.

The interpretation of perinatal adolescents' HIV disease as a social experience more than a medical one may seem at first glance to be counterintuitive, since they have been ensconced in the health care system since they were very young, and have been taking medicines throughout their lives. However, as Hunt and Arar have found, "patients, out of necessity, modify and adapt long-term illness understandings and self-care measures when applying them within the constraints of daily life" (Hunt and Arar 2001:351). All of the participants in this study knew, to greater and lesser degrees, that taking their medications faithfully was essential, that it would keep their viral load and T cells at optimum levels, and would keep them healthy, yet several of them had, at one time, refused to take them. Two participants, Keith and Sean, were non-adherent to a point that it was considered better to stop their medications altogether. Others were sporadically less than optimally adherent, and even those who were always or almost always adherent confessed to feeling sick and tired of taking the medications. I was surprised to hear Jeff, who had integrated his regimen very well into his daily routine, admit that he frequently thought about how sick and tired of taking the medicines he was.

The less dominant medical aspect of HIV owes some of its effect to the fact that HIV has become a disease in which people can live for long stretches of time as healthy

individuals. The traditional sick role (Crossley 1998) is no longer emphasized, and being HIV-positive has now become a kind of liminal state (Little et al. 1998). For the adolescents, being healthy and having none of the visible physical signs of disease gives them the chance to be normal, but it also makes them feel the urgency of their medical treatment less.

The desire for independence combined with medication fatigue, within an environment hostile to HIV, can also lead adolescents to rebel against adherence. The chronic nature of the disease can seem like a black hole that, at some point, can drain them of their energy and conscientiousness. The lack of control due to HIV in their lives is another element that weakens their resolve over time. The perinatally infected adolescents, in contrast to behaviorally infected adolescents and adults, had no control over how they got the disease, no control over when and how they were disclosed to, and no control over deciding when to begin treatment. There is evidence that being able to take responsibility for contracting HIV (as in those behaviorally infected), even if it is tinged with guilt, allows individuals to take control of and responsibility for their disease and its treatment (Plattner and Meiring 2006). Yet, some of the adolescents in this study seemed to embrace their blamelessness and accept their status and their management responsibility with more equanimity because of it. In general, the early disclosure to children seems to be a key element in this type of acceptance, and the subsequent assumption of responsibility for their disease. Paula, at 13, had already internalized her responsibility for taking her medications. Without hesitation, Jeff rated both the ease and the importance of taking his medicines very high.

Some of the adolescents in this study seemed to suffer because of this lack of control, feeling a sense of unfairness, which affected them even now as adolescents and young adults. They had a more difficult time accepting the circumstances of the disease, including engaging in their ongoing treatment. Keith thought it was unfair that he was the only infected child in his family; he had three uninfected siblings, and he felt like “an oddball.” Olivia did not say it was unfair, but her mother alluded to Olivia’s feeling that she was the only child her age who had this disease. Stephanie found it hard to accept her HIV at first because she did not know how she could have gotten it; her father did not have HIV, and she never knew her mother.

Disclosure to Peers

All of the participants shied away from sharing their status with friends and school mates. This was not only a personal choice but a socially constructed necessity, as the adolescents overwhelmingly agreed that there were social risks involved in sharing their status or even demonstrating an understanding of HIV and AIDS. Specific attitudes about keeping one’s business a secret also seemed to come into play. However, the adolescents disclosed to earlier were overall a bit more open about their status with friends.

Peer Relations

In this research study, more than half of the adolescents disclosed their HIV status to no one or to one friend. They were generally not inclined to disclose their status, because they felt it was not anyone’s business and because they anticipated a negative reaction. Many also described their school mates’ ridiculing or uninformed comments about HIV when the subject arose. These results indicate that these adolescents had very

few people with whom they could be open about their disease experience (Michaud et al. 2009) They also had not had much interaction with other HIV-positive adolescents, and some expressed little interest in meeting with other HIV-positive adolescents. The decision to keep their HIV status a secret, in addition to the reasons above, may also be made because the disease has no visible effects and the adolescents can pass as normal, healthy individuals (Goffman 1963; Michaud et al. 2009).

While peer support and openness about HIV status between friends was hypothesized to have an impact on adherence, and more of the adherent youth had disclosed to more friends than the less adherent individuals, the association was not consistent across the adolescent sample in this study. It is more likely that the adolescents who learned their HIV diagnosis at an early age adapted sooner and better to the disease in their lives, and thus were both more able to adhere well to their therapy and more comfortable disclosing their status to friends (Wiener and Battles 2006). The highly personal and potentially stigmatizing nature of HIV, however, was powerful enough that, even among some of the very adherent and adjusted adolescents, there was little disclosure. Lucy is the prime example of this; she was extremely adherent, yet insisted that she would disclose to no one outside her family.

It has also been theorized that the ability to share the difficult experience of HIV disease helps the individual to make cognitive adjustments that allow HIV to occupy a place in his or her “existing meaning structures” (Sherman et al. 2000:239), and improves their health and behavior (Abel et al. 2004). In addition, Sherman et al. found that disclosure to friends resulted in an increase in the HIV-positive individual’s CD4 level (Sherman et al. 2000). If disclosure to friends does indeed facilitate the acceptance of

HIV into the adolescent sense of self, is a part of the culture of childhood and adolescence (Sherman et al. 2000:240), and can improve health, then the cultural attitudes dictating secrecy, shading the truth, and lying about HIV can prevent significant advantages to the adolescent's physical and psychosocial health.

Sexual Relationships

The lack of peer support and interaction with other HIV-positive adolescents indicates that these adolescents are trying to keep their HIV disease in the background of their social relationships. They do not talk about their disease much even to the friends who are aware of it. While this may be part of the adolescent developmental stage that includes fitting in and being normal, the silence around their HIV status does raise concerns about their ability and willingness to discuss it with romantic and sexual partners. All of the adolescents knew that they should disclose their status to a boyfriend or girlfriend, and they were aware of the need for condoms during sexual intercourse, yet the study shows that the adolescents' description of future sexual behavior and what will actually occur or has already happened are not always the same. Of the seven sexually active adolescents in this study, two admitted not disclosing their status to at least one partner, and one said that he would not disclose to a partner until they had been together for a long time. This suggests the looming challenge of disclosing one's status to a sexual partner. As a study by Wiener and Battles has shown, adolescents who disclosed their status to more people were more likely to disclose to sexual partners, and those who scored higher in self-competence in relationships disclosed to more peers (Wiener and Battles 2006). While my study did not measure self-competence, it did show that many

of the adolescents were not well prepared, if at all, by their caregivers or clinical providers to disclose their status to peers.

Over half of the study participants mentioned that one of the worst things about having HIV was disclosure to others or the risk of transmission to a partner or children, both of which gain salience in the sexual relationship. Despite their knowledge of the importance of disclosure and safer sex, these adolescents have or anticipate having some difficulty with these behaviors in their sexual relationships. It seems that their HIV disease is experienced as “biographical disruption” (Bury 1982) at this point, where sexual relationships become part of their lives, even for those who were disclosed to early in life and appeared not to have felt this disruption previously. As the literature and the clinicians in this study have articulated (D’Angelo et al. 2001), the failure to disclose HIV status to casual partners is especially likely. Sex without condoms is also common (Dodds et al. 2003).

The most disturbing illustration of unsatisfactory disease management among the adolescents in this study was the combination of medication interruption and unsafe sexual activity. Both Keith and Sean had their regimens stopped in order to protect them from the viral resistance that their poor adherence was likely to cause. Their recent viral load results showed that they were not suppressing the virus completely during their treatment interruption. This is not surprising, but it does mean that their infectiousness, that is, the likelihood of transmitting HIV to a sexual partner, was elevated. The interview with Keith showed that during this time, he had had unprotected sexual intercourse with his girlfriend, because she had one past pregnancy and was currently pregnant. Sean was also sexually active, and did not disclose his status to his current

partner, though he said that he had used condoms. The decisions of the clinical provider to stop therapy and the decisions of the young men to engage in risky sexual activity risk result in an increased risk of transmission of HIV to their partners. Both cases are problematic. In Keith's case, his girlfriend was aware of his HIV status, but their sexual activity had been unprotected. In Sean's case, condoms were used, but his partner was unaware of his HIV status.

The decision to interrupt an adolescent's antiretroviral therapy should be revisited when a clinician is concerned that the adolescent is or will be engaging in sexual activity, especially unprotected sex.

Biomedical Implications and Provider-Patient Relationships

As argued above, many of the adolescents who participated in this research study saw the meaning of their illness in social terms more than in medical terms. The result is that they have not learned and internalized, 1) the effects of the virus if it becomes detectable or remains undetectable, 2) the meaning of adherence and how it can affect their health and their survival, and 3) the ramifications of their HIV disease management for their sexual partners. They are not approaching HIV disease as a medical circumstance that they cope with, but rather as a social problem that they bemoan (LeBlanc et al. 2003). They have not succeeded in making their disease management a routine, but rather attend to it when it is convenient. The fact that many forget, are too tired, or are too busy to take their medicines, are in a hurry, or don't have their medicines with them, is evidence of a failure to make taking medicine a habit. In addition, few in this study seemed to use reminder aids, such as pill boxes or alarms. Furthermore, if they did remember their medications, they still might not take them when they were in the

presence of friends. The more successful adolescents seemed to be more habituated to taking their pills, and would also, if necessary, find discreet ways to take them when among friends.

In this study, the adolescents who were able to remember, make time for, and fit in their medications, despite busy and changing schedules, social relationships in which disclosure had not occurred, and treatment fatigue, also had a somewhat more detailed understanding of the medical aspects of HIV and antiretroviral therapy. Yet all of the adolescents had gaps in their understanding of and ability to explain the clinical indicators of their health, their medicines' names, dosages and schedules, the definition of resistance, the relationship between adherence and clinical indicators and between adherence and resistance, and the effects of adherence, viral load, and resistant virus on transmission of HIV to sexual partners. Though most of them had taken, been given, or been expected to assume responsibility for taking their medicines, most had not increased their knowledge along with that adherence responsibility (Martin et al. 2007).

It is this deficit in a medical conceptualization and understanding of HIV and its ramifications that is one of the most important findings of this study. The adolescents' notions and actions regarding HIV disease, which are based on social, cultural, and medical notions and interactions within their environment, have a significant impact on the natural history of the human immunodeficiency virus. The level and consequent infectiousness of HIV, as it responds to medications, mutates during their absence, multiplies or decreases, depends on the individual's strict adherence to medications and attention to medical details, and has the potential to affect the individual's sexual partners (Wiener et al. 2007).

From both an individual medical perspective and a public health perspective, adherence to antiretroviral medications is crucial. Optimum adherence is necessary to suppress and maintain the virus at undetectable levels and to improve immune function. Transmission of HIV to sexual partners is rare among infected persons whose viral load is at very low (less than 1500 copies per milliliter) or undetectable levels (Quinn et al. 2000). Equally important is the effect of optimum adherence on reducing the chances of development of resistant virus. If resistance to medications develops, the infected individual will be obligated to change regimens and his or her choices of antiretroviral drugs are reduced. Moreover, if transmission of resistant virus occurs during sexual activity (Kourrouski and Lima 2009), then the recipient will enter treatment with a reduced range of efficacious antiretroviral drugs. Thus, the consequences of suboptimum adherence are felt at the individual level but extend to the epidemiology of HIV and the public's health.

The adolescents' situated construal of and response to their HIV results in a model of disease management that is apt to differ significantly from the biomedical model to which their clinicians subscribe. Among the study participants, the biomedical details of HIV and its management are understood, but the details are abbreviated. It is to be expected that a patient's knowledge is limited in comparison to the provider's, but these limitations can become problematic for the adolescent and young adult HIV-infected individuals when they are assuming responsibility for their therapy and becoming sexually active.

At the same time, the social and cultural dimensions of an adolescent's HIV experience, which dictate how they define HIV and develop strategies for managing it,

seem to be understood only superficially by the practitioner who provides care and treatment. More importantly, the provider may be unable or unwilling to take this experience into account when establishing a patient's plan of care. All of the providers in this study said that they discussed their patients' lives beyond the clinic, and they tried to accommodate specific issues in their prescription of treatment. For example, regimens were changed to twice daily dosages so that patients would not have to take medicine at school or risk forgetting them during the day. However, the primary goal of the medical provider was the health of the patient, as evidenced by satisfactory viral load and CD4 levels, and adherence to antiretroviral therapy to insure that health.

The distinction of HIV disease from many other chronic diseases lies in its infectiousness during symptom-free periods. In addition, the antiretroviral drugs are very unforgiving (Fisher et al. 2006) if not adhered to strictly. It is this part of the explanatory model of HIV (Kleinman 1978) – “the pathophysiology, course, and treatment” – that are approached differently by clinician and patient (Hunt and Arar 2001:349). In addressing these issues, disease management may be better perceived as a process developed by means of a provider-patient partnership, rather than as an ideology, “in terms of imposed professional expectations” (Trostle 2000:41).

Stigma: An Underlying Theme

The first five themes discussed above all share one construct: the stigma of HIV and AIDS. Disclosure, caregiver behavior, social attitudes, peer relations, and sexual activity were shaped by many elements of the adolescent's medical ecological context, but all shared the influence of stigma in making the adolescent's lived experience of HIV challenging. Only one adolescent mentioned the word stigma during our conversation,

and the word was never used during the mothers' focus group. A few of the adolescents who were asked if they knew what stigma meant said they did not. Yet, every participant's descriptions of their behaviors and attitudes or their peers' behaviors or attitudes reflected the underlying power of stigma that surrounds HIV and AIDS. As this study has shown, understanding and practicing adherence to therapy is facilitated or interrupted by a range of social, cultural, and medical contingencies. Underlying the interactions within these contexts is the continuing menace of HIV/AIDS stigma. In addition to the societal sources of stigma, in the cultural niche of adolescence, the presence of any differentiating characteristic can be cause for ridicule, as Olivia insisted in her interview. She said it did not matter whether it was HIV or asthma, the kids would pick on an affected child. Almost every adolescent recounted an instance of stigma – comments by school mates, a boyfriend, a relative – which led them to deny their status, lie to their friends, or be ostracized by a relative. The majority of the participants had decided that their HIV status was no one's business or best kept a secret, because they knew there would be negative reactions. Thus, the adolescent experience of HIV/AIDS evokes particularly harsh responses of “us” versus “them” (Devine et al. 1999; Gilmore and Somerville 1994) that plague the AIDS epidemic to this day, and explain the very common decision to keep one's HIV status a secret.

The mothers' focus group discussion also hinted at the presence of stigma, when the mothers discussed delaying disclosure of HIV status to their children, not disclosing their own status to family members, and receiving negative reactions from family members who learned of the diagnosis. Rita has never spoken to her in-laws since her husband's illness and death, and Teresa has not disclosed to her four older children. The

clinicians, too, described patients and parents who kept their HIV a secret from family, friends, and sexual partners. Carol recounted one poignant example which illustrates the impact of the social context and the ramifications of stigma and secrecy. The adolescent patient and her mother lived with the mother's parents but had not disclosed their status to the parents:

...the child...lives with the mom and the mom's parents and they've lived there the whole time I've worked here, and the grandparents don't know about their daughter or their granddaughter. So I'm thinking in my mind, how is she [the child] ever going to be disclosed? I mean, it's like a mega-secret. I don't even know how you live, it gives me like pain in my chest...I don't know how you do that every day, I mean, with medications and visits and everything, and actually the adolescent is, we are seeing the damage of that...she's going through adolescence and she's, it's just too much for her. I mean that's just too much stress and pressure to put on anyone, never mind a twelve-year-old, so I think she's starting to backlash at the mom now...[The mother's] reason... she has a very good reason, is that she is very aware of her parents'...thoughts, feelings on HIV, and she will be out like that, so she, her impression is that...she and her kids will be disowned, get out of the house, they're so strongly opinionated about it. I guess...it's not an option...she's dependent on them financiall, which I'm sure hasn't helped. I mean it could be totally different if she were more financially independent, had her own home, I mean, then it wouldn't be that much of an issue.

While this kind of enacted stigma was not experienced by most of the participants, the above instances of felt stigma were widely shared (Scambler 2009; Lekas et al. 2006).

Additional Factors Complicating Adherence

Adolescents' success at managing their HIV and achieving favorable clinical outcomes depends on other clinical factors. The history of their disease (e.g., higher and longer HIV replication following perinatal infection (Mullen et al. 2002)), perinatal infection with resistant HIV (Delaugerre et al. 2007), complications from opportunistic infections, side effects, changing medication regimens, and disease progression at the

initiation of HAART all have an impact on health outcomes (De Beaudrap et al. 2008) and successful, ongoing adherence. In addition, because there is evidence of developmental delay in some perinatally-infected individuals (Sherr et al. 2009), it is critical that adherence strategies be tailored to accommodate the adolescent's cognitive abilities. The prevalence of mental health problems also must be addressed, and these must be treated before or concurrently with the process of education about the details and responsibilities of disease management. The clinicians interviewed for this research agreed that about half of their adolescent patients had mental health issues that required attention, and this percentage is supported in the literature on HIV-infected youth (Lam et al. 2007).

Unexpected Findings

This study found that adolescents with perinatally acquired HIV were more likely to practice good adherence to medications and generally manage their disease well, if they were told their diagnosis at an early age (at or before age 10), had caregivers who were open about HIV, were themselves relatively open and accepting of their disease, and understood the clinical aspects of HIV and medication adherence. Of all the participants in this study, Katie appeared to reflect all of these themes in her life. Nonetheless, she was not in the group of adolescents who were extremely adherent and had consistently undetectable viral loads. She herself did not describe her adherence as perfect. So, why was she not able to maintain an undetectable viral load over time?

The reasons may stem from the history of Katie's HIV disease, which was not specifically explored in this study. However, apart from past resistance issues and treatment experience, Katie's inability to maintain an undetectable viral load by

achieving optimum adherence seems to be due to her relatively new status as an adult – she was 22 at the time of her interview – and the assumption of responsibilities related to this status. She was enrolled in college and talked about her busy school schedule and the fatigue that she felt was associated with it. She also chatted about the difference between childhood, when everything was taken of, and adulthood, when “All my money has to go on bills.” Even though she was disclosed to early and her mother was very open about the disease, Katie said that she did not take full, independent responsibility for taking her medicines until she was about eighteen. She believed that instruction on taking one’s antiretroviral medications should begin early, so that

when they do get on their own, it’ll be a lot easier for them to remember and to take them, and to really understand why they’re taking them and not just the fact...you want your viral load low, but also the fact that you don’t want to catch resistance to the medicine, because as fast as your virus will catch resistance to it, it’s not as fast as the pharmaceutical companies are going to be able to make medicine.

When Katie assumed control of her medications and adherence, she found it was difficult, especially when she reached adulthood and assumed adult responsibilities.

This turning point at which adolescents become adults, not in age but in responsibility, seems to reflect a point in the age continuum when adherence may become problematic. Bridget is another example. She had registered consecutive undetectable viral loads for over two years, but her recent lab tests showed a spike in these numbers. She admitted to her provider that she had not been taking her medicines like she used to, because she was busy with work. Bridget was eighteen at the time of her interview, and about to graduate from high school. Her viral load spikes appeared after graduation, when she was experiencing new, more adult responsibilities.

Conversely, Lucy did not fit completely within the explanatory parameters of ideal adherence, yet she was consistently undetectable and said she never forgot to take her medicines. She was not disclosed to at an early age, which was the most important variable in the study participants' adherence success. She was disclosed to at age fifteen, and was also strongly opposed to sharing her diagnosis with anyone. However, Lucy's mother was a vocal and active AIDS advocate, and very open about her own status. This may have contributed to Lucy's own personal acceptance that it was her fate to take medicines every day. She was one of the few adolescents who talked about being afraid of what would happen if she forgot to take her medicines. She seemed to have internalized the medical aspects of HIV and the concept of adherence as the basis for her disease management, even referring to her medicines, somewhat wryly, as her "three special friends." She knew the names of her medications and took a no-nonsense attitude toward them.

Interestingly, Lucy had a sibling in this research study, who was disclosed to at an earlier age than Lucy. This sibling was less successful with adherence, did not have consistently undetectable viral loads, and could not name the prescribed antiretroviral medications. This sibling had the same mother as Lucy, so there were similarities in the social environment of the siblings. There do not seem to be overt differences in the two adolescents based on the findings of this research, yet one had significantly better health outcomes and disease management. This puzzle may require further examination of prior disease history, as well as individual factors such as cognitive abilities and mental health issues.

The Role of the HIV-Positive Researcher Revisited

For many people with HIV or AIDS, these two labels – HIV and AIDS – are charged with enormous power. AIDS continues to connote severe deterioration and approaching death; HIV is an infection you can live with. The following exchange during the mothers' focus group, between a mother and me, with the perinatally infected daughter serving as translator (Spanish), touches on the distinction between HIV and AIDS:

Researcher: How's your mother doing, she forgets [her medicine] sometimes?

Mother: Yes.

R: How often?

M: Just two, two or three times.

R: Two or three times in how many, in how long?

M: In a week.

R: Two or three times a week.

M: Yes.

R: How about you [to daughter]?

M: She take it every day.

Daughter: I take it every day.

M: She undetectable.

R: And you're not?

M: No.

R: You're not undetectable.

M: No.

D: She got AIDS.

R: Yeah, but she can still be undetectable.

Sometimes I describe myself as having AIDS to try to rob the virus inside me of its dark power, to spit it out as I say the word, to show that a healthy, normal-looking person can have AIDS. I am not scary. I am not dying. However, in the interviews, I hardly ever used the term AIDS. In 22 interviews and one focus group, I said AIDS about ten times; in the first interview alone, I used HIV ten times. I know that I used the term HIV in order to make the discussion less threatening.

The fact of my own HIV infection is what turned my anthropological focus to HIV. Had my HIV test result been negative, I would now almost certainly be deeply immersed in the cultural construction of anything but HIV. This is an admission that I find difficult to make, knowing that the fear before my diagnosis, which made me shut out any reference to HIV, would probably have turned to relief and made me leave that AIDS problem to someone else. Having HIV has been a peculiar kind of education, supplementing my book learning and giving me the opportunity to look at other people's illness experience both emically and etically with a bit more clarity. I can wade into another person's experience, and then step back.

I have been able to take my HIV status and shape it into something good. But I have symbolic capital (Grove et al. 1997) that makes it easier for me to cope with this disease. No one important to me – family, friends, colleagues – has made me feel “discredited” (Goffman 1963:4). I have crossed a bridge of shame and can now deal with this almost completely as a clinical condition. But wait, that is not wholly true. When I decided that I would tell the participants in this study that I, too, was living with HIV, I was open, as I usually am, to having them turn the tables on me. Only one adolescent did, and while I answered her questions, I noticed some discomfort. Unlike the perinatally infected individuals, I was responsible for my infection. Shame resurfaces occasionally. And so I found I could empathize with these young people, on the brink of adulthood, as they begin to navigate emotional and sexual relationships with their HIV in tow. I knew the pressure of practicing safer sex as an adult, and I also knew the ease with which an adult can turn a momentary reckless eye, and HIV stares back. I realized how much harder this can be for adolescents.

Ten years after my diagnosis, I have forgotten one pill one time, and taken a dose late a handful of times. I use an alarm for both my morning and my evening doses. On a daily basis, my HIV is a virus that I control zealously, and my viral load is consistently undetectable. I want to make sure that my therapy options remain open, so I am obsessively vigilant about preventing resistance. I know that the virus may eventually become resistant to my current regimen no matter how adherent I am, but I do the only thing possible to ward off that evil. This is what HIV means to me, and the very different meaning that the adolescents have grown up with and shaped anew as they entered adolescence is something that I struggled with during this study. I am an adult virtually 100% adherent to my antiretroviral medicines trying to understand the immense challenges of teenagers and young adults who are not.

I thought that my being HIV-positive might help connect us as fellow sufferers. I thought it might make the participants more comfortable in the interview if they knew that this woman asking the questions had to take medicines like they did. However, the world of adolescence is not one I inhabit, and they and I knew it. HIV disease is a phenomenon to which each of us “brings to bear his or her lived experience, specific understandings, and historical background” (Finlay 2002:534), as this study has shown. Thus, my experience has been very different from the adolescents’, but it afforded me a position of commonality with them regarding living with an incurable disease, and living with the knowledge that these medicines are going to be “our special friends” forever. I occupied a space of “conscious partiality...a critical and dialectical distance between the researcher and his ‘objects’” (Mies 1983; quoted in Ellingson 1998:499) that allowed me to move into their HIV experience and back again into my researcher position.

I tried to listen to the adolescents' lives so that I could understand what challenged them most, and discover what paths they could follow to take control of their disease. These findings can now be shared with the clinicians and other service providers who care for these young people, and recommendations for improving disease management can be proposed. Finally, the understanding of living with AIDS must be shared with the world, that we might disable the stigma and learn to embrace each one of these adolescents – as well as 33 million others – as one of us.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

This study of HIV disease management in medical ecological perspective among perinatally infected adolescents has illustrated the challenges that young people face in learning to cope with a lifelong chronic illness. Since the advent of HAART in the mid-1990s, a generation of children have grown into adolescence and adulthood. For the adolescents in this study, all born before or just at the introduction of HAART, their survival into their teens and twenties is a future their mothers did not think possible when they were born. Since then, these mothers and thousands of other parents, caregivers, and health care providers have been exploring and developing ways in which these children and young adults can best take control of their disease both medically and socially, can diligently manage a serious, incurable disease in order to remain healthy, and, at the same time, live a normal, untroubled childhood and adolescence.

The management of HIV disease remains complicated, despite great improvements in treatment, and the stigma that attaches to those living with the disease remains pronounced. When these difficulties are encountered during the development of independence and maturity in adolescence, the process of gaining control in a healthy way can be daunting. What are the elements in this process that help or hinder the successful management of HIV, in particular, the successful adherence to HAART? What cultural and social influences impinge upon adolescents' decisions about health-related behaviors? Though this study was primarily an exploratory ethnographic analysis with a very small sample of adolescent participants, it nonetheless provides a rare and

important glimpse of their perspectives on living with HIV. This study has drawn some conclusions in answer to these questions, though it has also illustrated the uniqueness of each young person's lived experience and his or her individual approach to making a place for HIV in his or her life.

Though the study was limited in scope, it has generated a number of recommendations that health care providers, social service providers, caregivers, and adolescents can explore, collaborate on, and implement in order that perinatally infected adolescents move smoothly toward adulthood in good health.

Conclusions

The most important conclusion drawn from this research is the importance of early disclosure to the child of his or her HIV status. Closely related to this, because it may in fact facilitate early disclosure, is the parent or other caregiver's attitude of openness and confidence toward dealing with the challenges of HIV, in herself if she is the biological mother, and in the child's life regardless of who the caregiver is. Some of the adolescents in this study had lost parents to HIV or had been taken from parents who had substance abuse problems, but if they had been brought up by caregivers who faced HIV with equanimity and acceptance, then the adolescent had the opportunity to adapt to his or her own HIV more easily and competently. The earlier in life that this process of identification, understanding, and adaptation began, the more likely it was that a place for HIV would be established in the adolescent's life and be less of a disruption (Bury 1982). This would be a place where the importance of HIV treatment was prominent, but the HIV per se was not.

Another key conclusion was the importance of a medical meaning of HIV in the adolescent's life. This would not only ensure the understanding of the implications of HIV treatment, but it would replace, or at least shift to a less powerful position, the more troubling social and cultural connotations of HIV. HIV would be less the scary secret, and more the chronic nuisance. If adolescents learned how to make the medications a routine part of their daily lives, they would be able to make HIV management a normal part of life. Hence, they could feel more normal, more like other young people.

A third conclusion that is drawn from this study is the adolescent's need for a better understanding of adherence, viral resistance, and HIV transmission risk. This lack of understanding seems to be due in part to the failure to treat children and adolescents as capable participants in their care and treatment. As the clinicians and the literature both point out, the simultaneous coddling and commanding of children does not give them the tools to begin making decisions and taking responsibility, and results in difficult and often unsuccessful transition to adult clinical care (Wiener et al. 2007).

In addition, being uninformed about the ramifications of adherence versus non-adherence puts the adolescent at risk for therapy failure and poor health outcomes, and his or her sexual partners at greater risk for contracting HIV. Because adolescents with perinatally-acquired HIV have been prescribed antiretroviral therapy from an early age, they are likely to have some resistant strains of HIV (Mullen et al. 2002). It is also possible that they were infected with a resistant strain carried by their mothers (Delaugerre et al. 2007). For this reason, adherence is extremely important; it makes a lower viral load and thus reduced risk of HIV transmission to partners more likely, and it also reduces the risk of further resistance to the adolescent's current or future regimens.

The adolescent's HAART and viral resistance history notwithstanding, it is of utmost importance for these adolescents to understand and practice good adherence, both for their own health and for current or future sexual partners.

Finally, this research points to the need for an exchange of chronic illness representations held by health care providers and adolescents. Because many perinatally infected adolescents are today living lives relatively free of symptoms, opportunistic infections, and medication side effects, there may be a complacency in their attitudes toward adherence and toward the key health indicators, viral load and CD4 level. This is also associated with their lack of comprehensive knowledge about HIV infection and its ramifications. On the other hand, health care providers need to know the beliefs and behaviors in the adolescents' lived experience of HIV that are nonnegotiable, and work with the patients to find a model of HIV disease management that conforms to both the medical and the social and cultural demands of practitioner and patient. These imperatives need to be better understood, accepted, and integrated by both parties, if successful disease management and, therefore, favorable individual and public health outcomes, are to be achieved.

Recommendations

The following recommendations are directed toward service providers, parents and other caregivers, and adolescents with perinatally acquired HIV disease. The adolescents who are seen at the USF pediatric clinic have access to a variety of professionals in addition to the clinicians: social workers, medical case managers, mental health professionals, nutritionists, nurse educators. Many of them also have access to support and social services through community-based case management agencies. All of

these professionals in the HIV service delivery system have the potential to guide adolescents as they navigate the health care system, prepare for transition to adult care, and continue their daily management of their HIV disease. These recommendations could be implemented in a number of the venues through which adolescents find care, treatment, and support:

1. Parents and caregivers of perinatally infected children should be counseled about disclosure beginning before the child is of school age. Their fears and anxiety, as well as their lack of medical knowledge, should be addressed. Disclosure should be delineated as a process (Lesch et al. 2007;Ledlie 1999; Lipson 1993), with information benchmarks developed according to the child's age (and cognitive abilities), with identification of HIV by age 10.
2. The roles and responsibilities of parent/caregiver and child regarding antiretroviral therapy should be clear-cut and age appropriate. Caregivers should be counseled on setting up a plan for the gradual delegation of responsibility to the child, which includes the continual monitoring of children and adolescents to ensure that they are adhering to their medications successfully and not assuming full responsibility prematurely (Marhefka et al. 2008).
3. Counseling should be available and providers should work with biological mothers (and other family members) to cope with their own HIV status, so as to engender the openness that is necessary to accept the disease without fear and shame before disclosing to the child. It is important to know that

assistance to both the infected child and the family may need to be ongoing (Wilfert et al. 1999:165).

4. Adolescents must be given thorough, if basic, instruction on antiretroviral therapy, adherence, resistance, the implications of HIV adherence and resistance for transmission to sexual partners. They should understand the meaning of the viral load and the CD4 count, be encouraged to know their most recent lab results, and know the names, dosages, and schedules of their medications. This clinical instruction should begin with children as soon as they learn their HIV diagnosis, and before they are given responsibility for medications. The discussion should continue and become more detailed as children and adolescents are given increasing responsibility.
5. Provider and patient models of HIV disease management (Hunt and Arar 2001:353) should be constructed, compared, interpreted, and integrated to form a model of consensus that will promote success from the perspective of both the provider and the adolescent patient. This model can include a cost/benefit examination of adherence and disease management, which includes an “adaptive compromise” between providers and patients (Armelagos et al. 1992:42). Providers have to begin appropriate delegation of responsibility to the child while understanding the adolescent’s real social and cultural obstacles to good adherence. Partnership must be forged early on and continue throughout and be enhanced during adolescence, and the locus of control, as well as responsibility for successes and failures, must be shared.

6. Reminder tools should be presented to and encouraged among adolescent patients. Pill boxes, small keychain pill containers, alarms on cell phones and watches, text messages, and other reminders that can be used wherever the adolescent is and can be discreet are more likely to be used and to be effective. This will enable adolescents to integrate the medications into their daily routines.
7. In keeping with nurse practitioner Ed's endorsement, adolescent patients should be encouraged and allowed to have friends, and especially sexual partners, accompany them to their medical visits so that the disease and its implications can be explained and demystified for the adolescents' peer networks. This should be part of ongoing encouragement of adolescents to share and talk about their disease with trusting peers.

Suggestions for Future Research

As an exploratory study of perinatally infected adolescents' lived experience with HIV disease, this research was limited to a biocultural examination of the proximate contextual factors that influenced their decisions and behaviors surrounding HIV disease management. A number of issues were raised by this research that should be addressed in subsequent studies.

Mental health problems and treatment were not the focus of this research and were not discussed by the adolescents, but the clinicians in this study, as well as some studies documented in the literature on HIV-infected adolescents, acknowledged the prevalence of mental health diagnoses and their impact on successful disease management, especially medication adherence (Williams et al. 2006; Dodds et al. 2003;

Murphy et al. 2001). Whether higher rates of psychiatric problems are due to HIV itself or to the socioecological environment (household and caregivers where HIV is present) is another question requiring further investigation (Williams et al. 2010). Since mental health disorders in adolescents are also often underidentified (Murphy et al. 2005), more attention to mental health in adolescents and specific research on HIV-infected adolescents may shed light on whether and how mental health influences adherence outcomes.

The presence of psychiatric symptoms may also have an impact on substance use in adolescents (Williams et al. 2010). One of the clinicians in this study maintained that among those adolescents who had problems with medication adherence, many also had substance use problems. Thus, with or without accompanying mental health disorders, the association of substance use with lower adherence to medications is another issue that merits further study.

Antiretroviral therapy today has vastly improved in terms of pill burden, complicated pill schedules and ability to tolerate the medications. There is also a greater availability of alternative regimens as new drugs have been developed and approved. This means that adherence problems due to difficult regimens and side effects have been attenuated. None of the participants in this study had serious problems with side effects, yet this may be one factor that affects optimum adherence (Kourrouski and Lima 2009). In particular, adolescents who have been on HAART since birth, may have already changed regimens several times, and have fewer options available to them. Thus, an exploration of the history of adolescents' drug regimens, resistance to certain drugs, and

the difficulties they are experiencing with their current medications may shed insight into the adherence issues of this particular population.

Given that the adolescents' HIV disease management was situated in medical and social spheres of influence, in-depth observation of these environments would elucidate additional factors that affect decision making about adherence and disclosure, as well as the experience of both stigma and support. Shadowing adolescents as they navigate their school, family, and clinical relationships, coupled with focus groups with adolescents, both HIV-positive and HIV-negative, would have the potential of illuminating the social conditions and cultural domains (Trotter 1997) that engender conceptions and perceptions of HIV, AIDS, adherence, stigma, and acceptance. Such up-close observation may also reveal the "situational temptations" (MacDonell et al. 2011) that adolescents face in their daily experience with HIV disease.

Observation of and further in-depth interviews with clinicians and patients are necessary in order to discover and understand the impact of the clinician-patient interaction on adolescents' acceptance of responsibility for disease management and their ability to fulfill that responsibility successfully. This study showed very different interaction styles of the clinicians, and further study might determine the interaction styles that are most effective in connecting with adolescents, encouraging learning and the assumption of responsibility, and improving adherence and health outcomes.

The comprehensiveness of the USF pediatric system of HIV medical care allows patients' multiple needs to be met at one location, yet further study would answer questions about whether adolescents' dislike of long clinic visits is ultimately detrimental to their engagement in their own care and treatment. It is also necessary, now that

perinatally infected children are reaching adulthood, to see how the pediatric model of care, in which the locus of responsibility rests heavily with the provider, affects adolescents' and young adults' readiness for transition to adult care (Foster et al. 2007; Wiener et al. 2007). An examination of the efficacy of the transition preparation program at the pediatric clinic and the need for implementation of best practices are also needed, as adolescents may find the transition more difficult than anticipated (Fair et al. 2010) and many will not successfully transition despite preparation at the pediatric clinic (Barrett et al. 2010).

The survival of perinatally infected children into adulthood means that these individuals must confront their futures, which includes having children. While the present study did not focus on future goals, a number of the participants mentioned the goals of continuing their education, getting a job, and having children. Part of disease management, therefore, will mean preventing second-generation mother-to-child transmission, which has been referred to as "super-vertical" transmission (Mitchell et al. 2008). Adherence and viral suppression become increasingly important for young infected pregnant women, if they are to reduce the probability of transmission to their newborns. This is especially important since second-generation perinatal transmission may involve virus that is resistant to certain antiretroviral drugs (Brogly et al. 2007).

Finally, given that many of the participants in this research disclosed their HIV status to very few friends, and most had little or no contact with other HIV-positive adolescents, a study of the barriers to social support among perinatally-infected adolescents is warranted. The positive effects of this kind of peer support on disease

management, including adherence, and on other healthy behaviors require further study (Dodds et al. 2003).

Coda

Caregivers and health care providers, and others who are aware of the adolescent's diagnosis, must be given the tools to engender a narrative of hope in adolescents with perinatally acquired HIV. Only one participant in this study had been given the opportunity to see her HIV status in a positive light and foresee a meaningful future:

even though I'm just another person on this planet, like just realizing that I can make a difference, and that's just kind of helped me a lot... I'm thinking like maybe, as a big picture, what that would mean would probably be like working for the WHO in like Africa and China and places like that, you know. So I would be making a difference to people around the world, I guess, who are HIV positive or not. [Rachel]

Adolescents with perinatally acquired HIV disease are now reaching the age of thirty, and it is incumbent upon those around them to guide them, from early childhood and through adolescence, to anticipate an adulthood of possibility and productivity. This can be done during adolescence by encouraging them to push the boundaries of their disease and to plan for their futures. Whether or not this entails work related to HIV and AIDS is, of course, up to each of them, but they need learn that with the proper knowledge and management of their HIV, this disease need not manage them.

I end with a passages from two anthropological works written about another chronic disease, epilepsy, which acclaim the power of social and cultural narratives:

[N]arrative is uniquely suited to represent illness and reality as open to mystery, potency and change (Good et al. 1994:837).

Possibilities for transformation in the conditions of the afflicted are kept alive. Multiple perspectives and divergent interpretations are

encouraged. Alternate sources of power for potential transformations are conjured; social actors reject the anticipated; hope is engendered (Kleinman et al. 1995:1320).

The lived experience of adolescents with perinatally acquired HIV needs to spawn new narratives of power and reinvention, both for the adolescents' personal growth and for society's conversion, narratives which resist the orthodoxy of stigma that has governed HIV and AIDS for too long. We must now draw on the lessons discovered in this study to facilitate the acceptance of HIV and consequent successful disease management among those living with this disease.

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APPENDICES

Appendix A: Adolescent Medication Questionnaire

Adherence Issues among Adolescents Perinatally Infected with HIV

Adolescent Medication Questionnaire

Part 1: Personal Information

Name: _____ **ID Number:** _____

Age: _____ **Date of Birth:** ____/____/____ **Gender:** Female Male

Ethnicity: Hispanic Non-Hispanic

Race: Black White More than one Other (Specify) _____

Part 2: Naming medications and describing medication schedule

2.1 What medications do you currently take for your HIV disease?

2.2 What other medications do you take, besides your HIV meds? (If no other medications, write none.)

2.3 Complete the table for your HIV medications only.

Medication Name	How many per day?	When do you take it/them?	Any specific instructions (with/without food, at a specific time, etc.)

Appendix A: (Continued)

Part 3: Medication Adherence

3.1 Thinking about the last two weeks, how many **days** did you skip an HIV medication for any reason?

0 1 2-3 4 or more

3.2 If you skipped an HIV medication in the last two weeks, was it

A single pill

A single medication (all of the pills for that day)

All of your HIV medications on that day

3.3 What were the reasons that you skipped your medication in the past two weeks?

3.4 What things make it difficult for you to take your medications as instructed?

3.5 How often would you say you skip a pill or pills overall?

Once a month Twice a month 3 or more times a month

3.6 Does your doctor or nurse talk to you about taking your medications?

Yes No

What does he/she say about taking your medications?

3.7 Do you talk to your doctor or nurse about any problems or issues you have with your medications?

Yes No

Appendix A: (Continued)

What does he/she say? What does he/she tell you to do?

3.8 On a scale of 1 to 10, how well does your doctor or nurse understand your issues, challenges, problems, and experience with taking HIV medications?

1 2 3 4 5 6 7 8 9 10
/_____/_____/_____/_____/_____/_____/_____/_____/_____/____/

1—Doesn't understand at all -----10 Understands everything

Appendix B: Semi-structured Adolescent Interview Guide

1. When were you told that your illness was HIV disease? Who told you? What were the circumstances?
2. How did you feel when you learned your diagnosis?
3. Tell me what it is like for you living with HIV. (Probe for physical effects, illnesses and hospitalizations, change in medication regimen, social support, social difficulties, stigma, goals and the future, medical care and providers, family support/difficulties.)
4. Describe a typical day in your life. How do you spend your weekends and free time? (Probe for how often HIV is part of that day, how often they think about it, etc.)
5. What medicines do you take for HIV? Describe your regimen – number of pills per day, time of pill-taking, other instructions (with/without food, spacing of different pills, refrigeration, etc).
6. What problems do you have that you feel are associated with taking your HIV meds? (Probe for physical side effects, complicated regimen, keeping medications hidden from others, fitting medication taking into schedule.)
7. How difficult is it for you to take your pills every day and according to the directions?
8. Do you ever not take your HIV meds? Under what circumstances?
9. What does adherence mean to you? (Explain adherence.)
10. Describe your relationship with your health care providers – doctor, nurse, social worker, mental health professional.
11. How would you rate your HIV health care?
12. Have you disclosed your illness to your friends? Others? For those to whom you have disclosed, how did you choose these people to share your diagnosis? What were the circumstances? How did the person react to this news? For those not disclosed to, why haven't you disclosed to these people?
13. What is your family life like? (Probe for household makeup, socioeconomic situation.) What other family members are positive? (Probe for health care, medication regimens, attitudes toward HIV and medications of positive family members.)

Appendix B: (Continued)

14. Do you have a boyfriend/girlfriend? How old is he/she? Does he/she know about your HIV? Do your closest friends have boyfriends/girlfriends? How important is having a boyfriend/girlfriend to you?
15. What does safer sex mean to you?
16. (If participant has boyfriend/girlfriend) Are you in a sexual relationship with your boyfriend/girlfriend? (If yes) What does that mean? Are you practicing safer sex? What does that entail?

Appendix C: Clinician Interview Guide

All questions pertain to perinatally infected adolescents.

1. How long is a typical care visit with an adolescent?
2. What percentage of the visit time is comprised of you, the provider, talking or explaining?
3. What percentage of the visit time is comprised of the adolescent patient speaking or explaining?
4. Do you set aside any time during the visit to speak to the adolescent privately?
5. How involved are your adolescents in their personal treatment and management of HIV?
6. Do you conduct sexual histories with your adolescent patients?
 - All? Which ones?
 - What is included in your sexual history?
 - Do you discuss sexual activity and risk with your patients? What do you include in this discussion?
7. How often do you talk to your adolescent patients about adherence?
 - What does adherence counseling include?
 - How involved are your adolescents in their individual treatment plan?
 - In your opinion, what is the biggest barrier to adherence among your adolescent patients?
 - In your opinion, what is the most important facilitator of adherence among your adolescent patients?
8. What percentage of patients seen **WITHIN THE PAST THREE MONTHS** received the following screenings and/or assessments?

Mental Health Screening:

None 1-24% 25-49% 50-74% 75-100% Don't know

Alcohol & Substance Use Screening:

None 1-24% 25-49% 50-74% 75-100% Don't know

Appendix C: (Continued)

Behavioral Risk Assessments:

None 1-24% 25-49% 50-74% 75-100% Don't know

STD Screening:

None 1-24% 25-49% 50-74% 75-100% Don't know

9. What percentage of your patients seen WITHIN THE PAST THREE MONTHS has the following diagnoses?

Hepatitis C _____% Mental health disorder _____%

Drug and/or alcohol problems _____% Any STI _____%

TB _____% AIDS (Progressed to AIDS) _____%

OI _____% Other complicating condition _____% What conditions?

10. What percentage of your patients do you estimate consult with a traditional healer and/or complementary and alternative medicine (CAM) practitioner or engage in alternative medicine practices?

11. A. What do you see as the three major health care issues or needs among the adolescents you serve at this clinic?

1. _____

2. _____

3. _____

B. Of their parent(s) or caretakers?

1. _____

2. _____

3. _____

Appendix C: (Continued)

C. What do you see as the three major non-health-related issues that affect the adolescent's health and health care?

1. _____
2. _____
3. _____

12. Describe the relationship between the adolescent patient and you, his or her health care provider.

13. What barriers do you experience in providing the best possible care to HIV-infected adolescents?

(Suggest the following, if necessary.)

- [01] Limited Resources
- [04] Lack of Provider Expertise
- [05] Other Health Priorities
- [06] Lack of Provider Interest
- [07] Patients/Clients Not Aware of Services
- [08] Issues of Confidentiality
- [09] Issues of Cultural Competency
- [10] Language Barriers
- [88] Other *specify* _____

Appendix D: Focus Group Protocol

Before the focus begins:

- **Have copies of consent form. Collect signed consent forms.**
- Have pens, sticky notes, dots, name tags, and voice recorder ready.
- Set out snacks.

Introducing the focus group activity:

1. Go over ground rules.

- Confidentiality – keeping what is said in the group private. Assure them that anything said during the focus group will not be shared with their parents or anyone at the clinic, except when the research is finished, and none of their identities will be shared. It will be general things that I found out, or I will refer to you as a participant.
- You can use your ID number instead of your name. When you speak, say your number first.
- Only one person speaks at a time.
- Respect everyone's input. Remember that there may be differences of opinion and experience.

2. Explain research study.

This is a study in which I want to understand living with HIV and managing HIV in the everyday lives of perinatally infected adolescents, from their perspective. We know medically what HIV is and how it is treated. I, as an adult with HIV, understand some of the challenges that older women have when they're living with this disease. Adolescents and young adults will deal with their challenges differently, and for those who were born with HIV, and have had to take medications and see the doctor regularly, and maybe have had other illnesses, and have family members with HIV, the experience will be different as well. This study is an opportunity for youth to tell their stories, to share the challenges they face, to share with us ways in which they have managed well with the disease, the experiences that are their own and affect the way they deal with HIV

Appendix D: (Continued)

in their relationships with other people, in their health care, in their medication issues, in their family life.

We at FAN have perinatally infected youth who live in many different kinds of family and household situations. One of the unique relationships for these youth, however, is that between them and their biological mothers. Since all of you are infected with HIV and transmitted the virus to your child, there are no doubt interactions, attitudes, problems, benefits of this mother-child relationship that influence the health and wellbeing of your child, as well as the way in which your child approaches her/his HIV disease and life in general.

In a focus group such as this, we bring together a group of people who focus on a topic that is of interest to the researcher. There are several topics that I want you to think and talk about during this focus group. I will introduce a topic, and pose some general questions, and then you will take turns discussing the topic, responding to other people's ideas, and together presenting your thoughts on those topics. We may use the sticky notes and dots for some of the questions, so I may pose a question and have you write down some ideas, then put them in order of importance using the dots. Then we will share what you've written as a group. In a group discussion, it is important to hear from everyone, so I may need to cut in at some points in order to let other people speak. Since we will have only about 10 minutes per question, it will be important to try to limit your responses to a minute or two, if possible.

Appendix D: (Continued)

3. Introduce Focus Group Topics/Questions for Discussion

1. Talk about your diagnosis. Did you disclose to family and friends? What were the reactions of your family and friends?
2. Talk about how you feel today about being HIV+.
3. What is the worst thing about having HIV?
4. What is the best thing about having HIV?
5. Talk about what it was like learning that your child was infected with the virus.
6. When and how did you disclose your disease and his or her own disease to your child?
7. At what age was the child told he/she had HIV – the word HIV was used.
8. At what age did you want to disclose, i.e., did you have any misgivings about disclosing when you did?
9. Discuss the strengths and weaknesses of your health care. How happy are you with (how would you rate) your health care?
10. Discuss the strengths and weaknesses of your child's health care. How happy are you with (how would you rate) your child's health care?
11. What do you know about HIV and your own health indicators relating to HIV (viral load, CD4 count, etc.)?
12. How would you rate your adherence to your medications?
13. What do you know about antiretroviral therapy – the drugs, the medication schedules, the effects, the side effects, the effectiveness, drug resistance, etc.?
14. Discuss your child's medication regimen and the responsibilities, roles, involvement of you and the child in the child's taking of and adherence to the medications. How much independence, and in what areas, does your child have in her/his management of HIV in her/his everyday life?
15. In thinking about the management of HIV in your life and your child's life, what do you do to stay healthy and to ensure your and your child's longevity? Include all things, not just your doctor visits and antiretroviral therapy.

Appendix E: Codes for Analysis

Adolescents Interviews

Adjustment
Adolescent Responsibility/Independence
Age of Disclosure
Age of Disclosure-Early
Age of Disclosure-Intermediate
Age of Disclosure-Late
Benefits/Social Supports
Caregiver Involvement in Medication
CD4 or VL Mention
Cultural Factors
Disclosure to Boy/Girlfriend/Sexual Partner
Disclosure to Friends
Disclosure to Others
Family Stability
Family Support
Future Goals
Health Status
Length of Current Regimen
Loss of Parent/HIV+ Parent
Lying
Medication Adherence
Medication Name Knowledge
Obstacles
Peer Support
Provider-Patient Relationship
Psychosocial Issues
Resistance
Risky Behaviors
Secrecy
Sexual Activity
Stigma
Understanding of HIV/Resistance

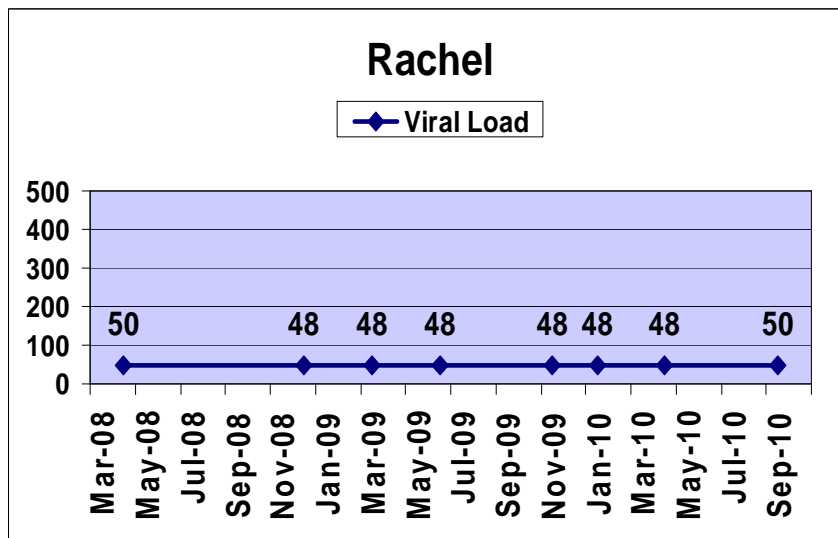
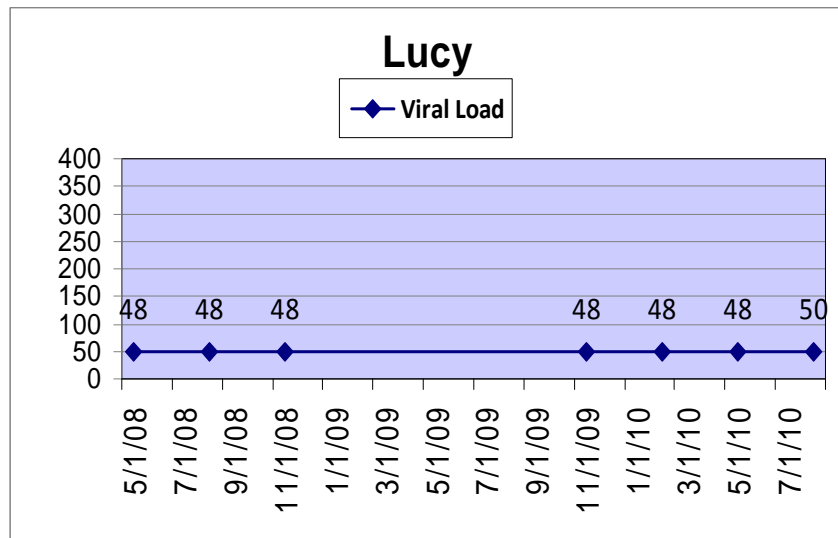
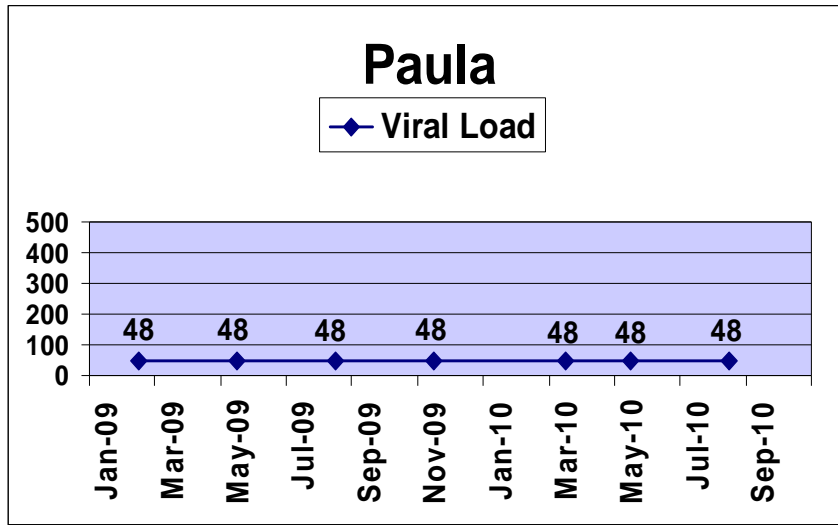
Clinician Interviews

Accidental Disclosure
Adherence
Adolescent Engagement
Adolescent Issues
Alternative Therapies
Barriers to Adherence
Barriers to Care
Developmental Delay
Disclosure
Legal Issues
Medications
Mental Health Problems
Relationship with Patients
Resistance and Labs
Secrecy
Sexual Activity
STIs
Substance Use

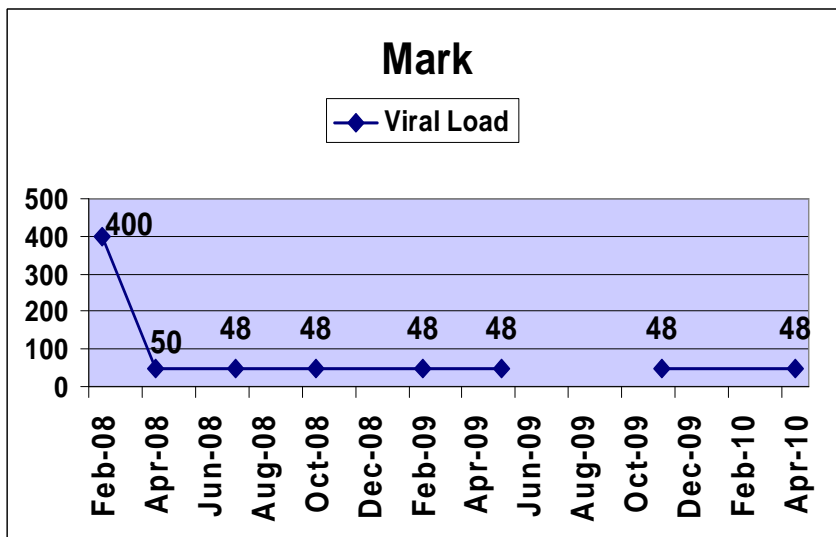
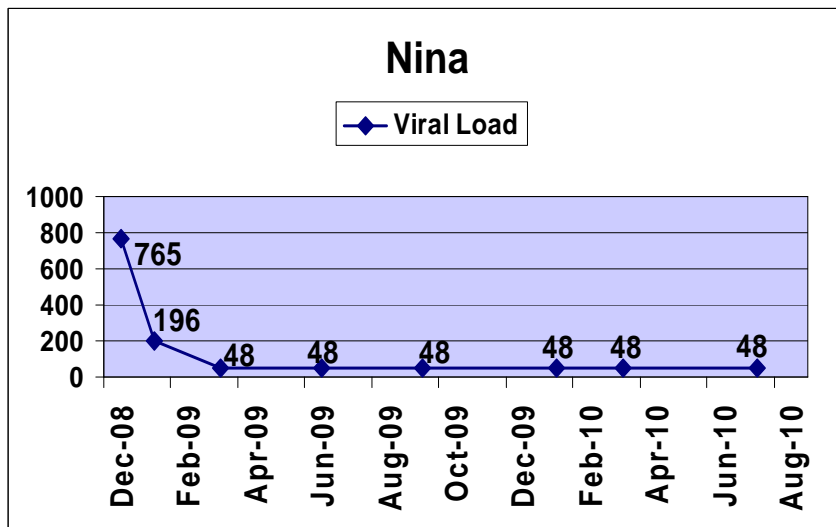
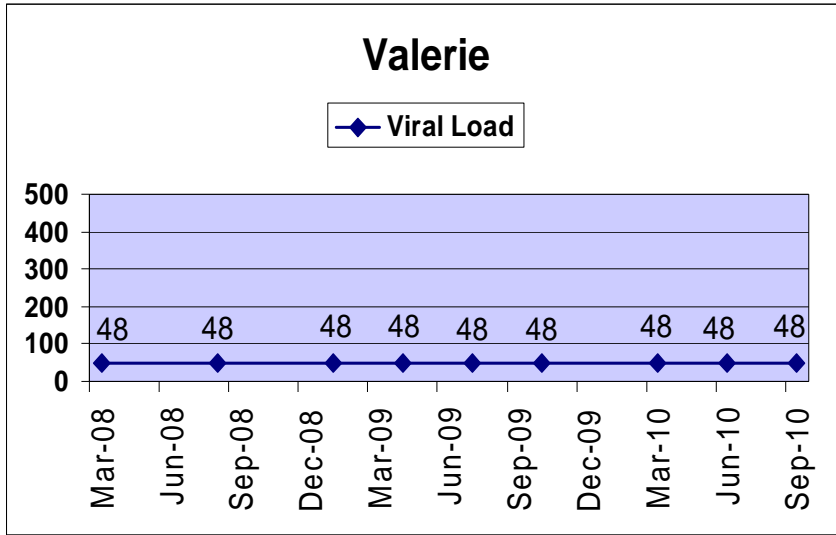
Mothers' Focus Group

Child's Adherence
Child's Independence
Disclosure to Child
Distrust
Health Care and HC Providers
Medications and Adherence
Mother's Own Diagnosis

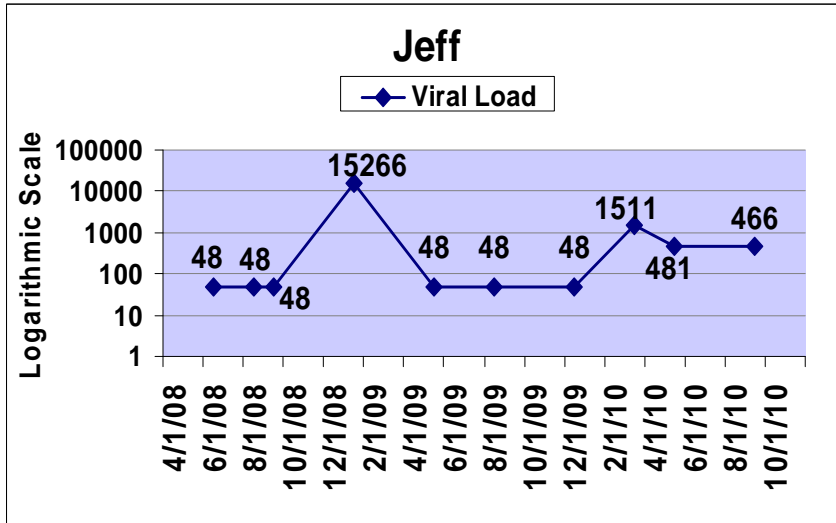
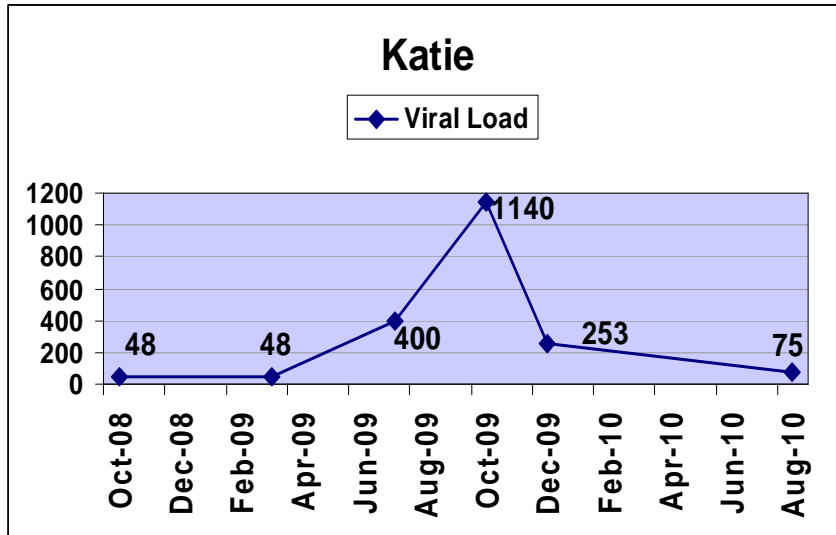
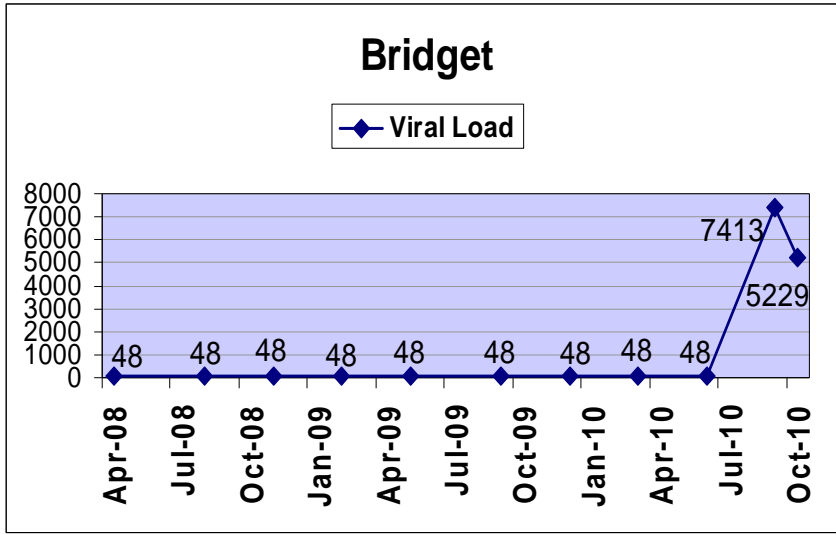
Appendix F: Graphs of Adolescent Viral Loads



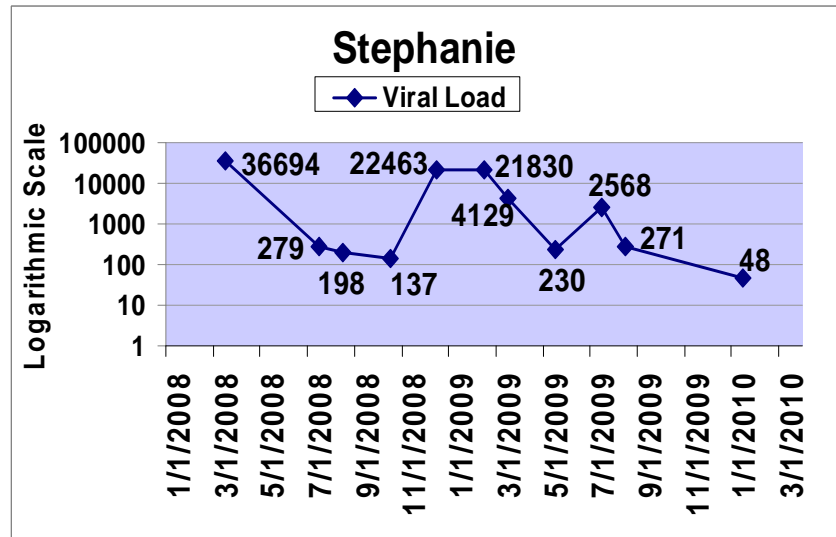
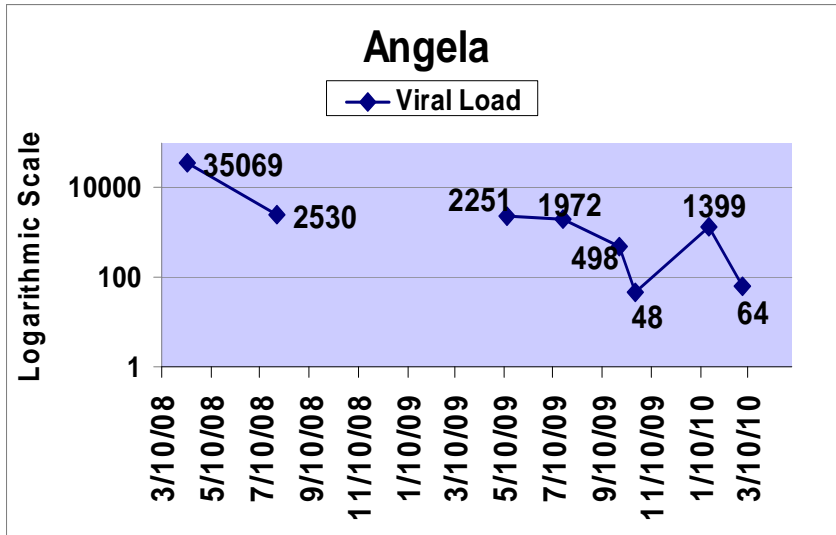
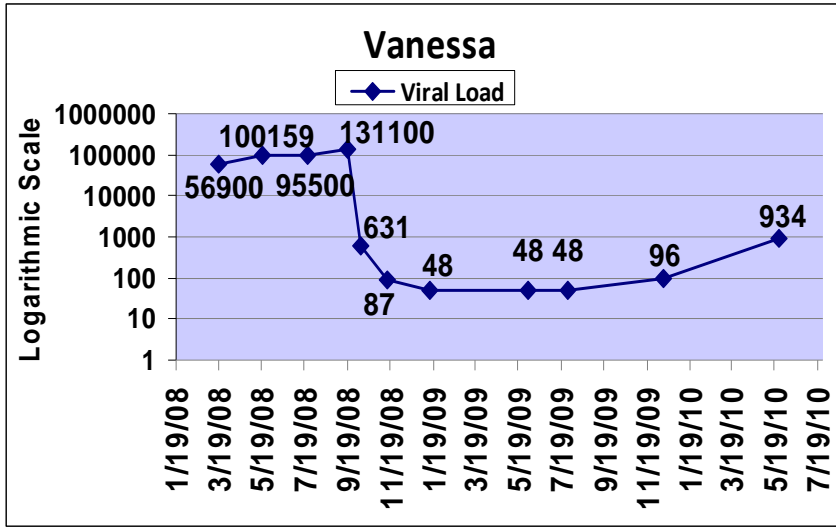
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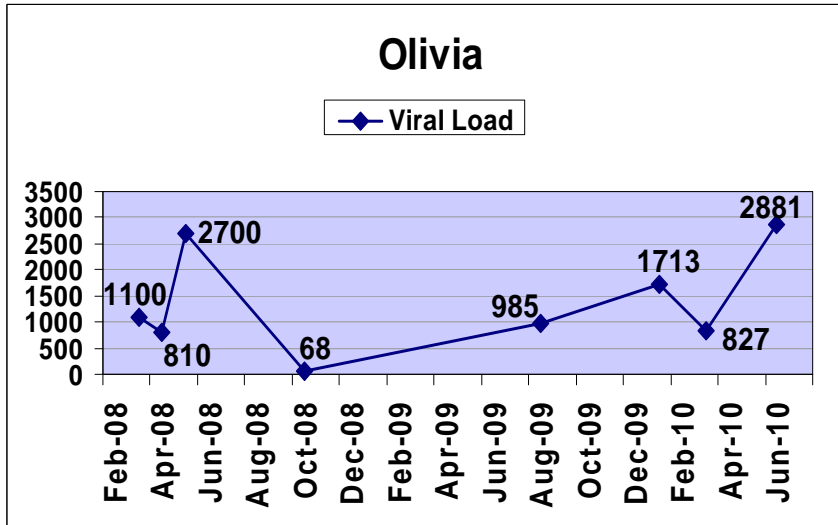
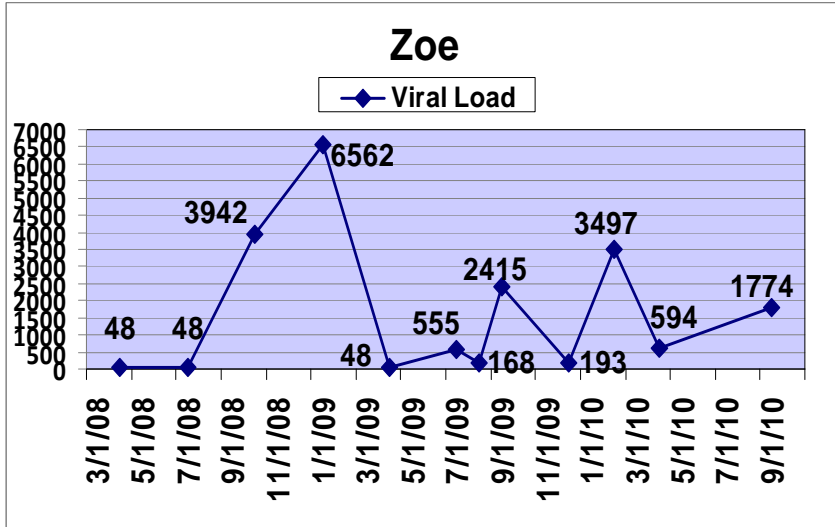
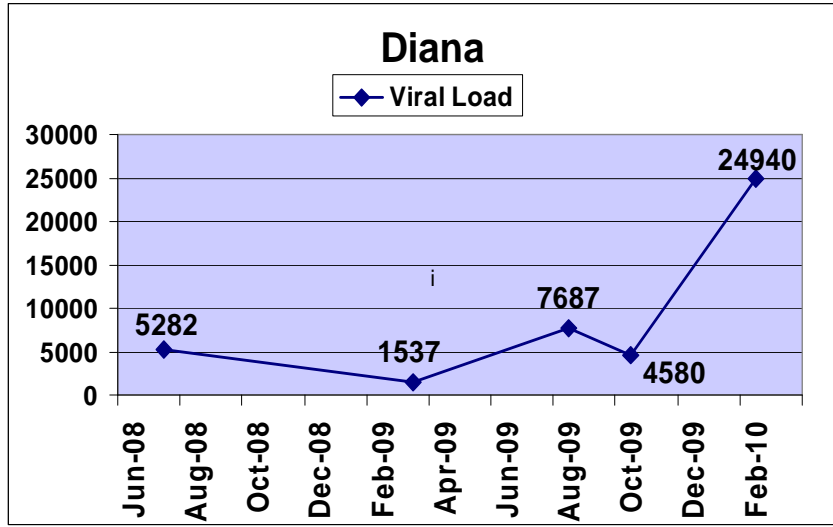
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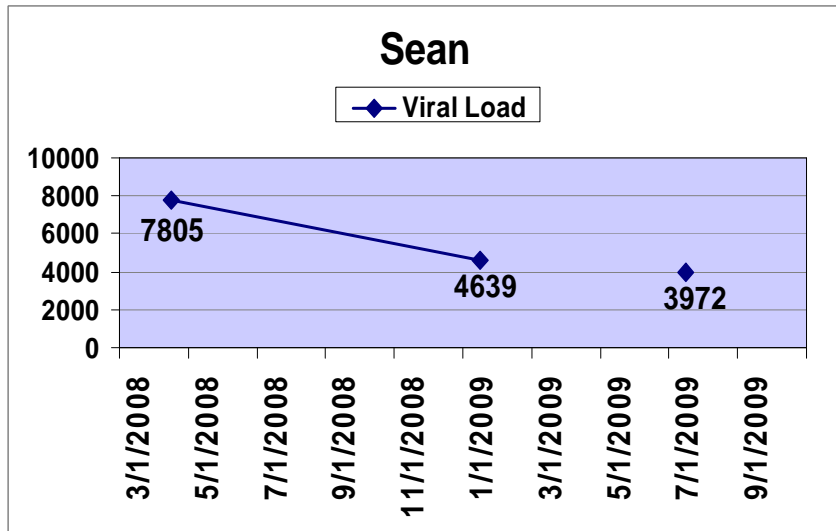
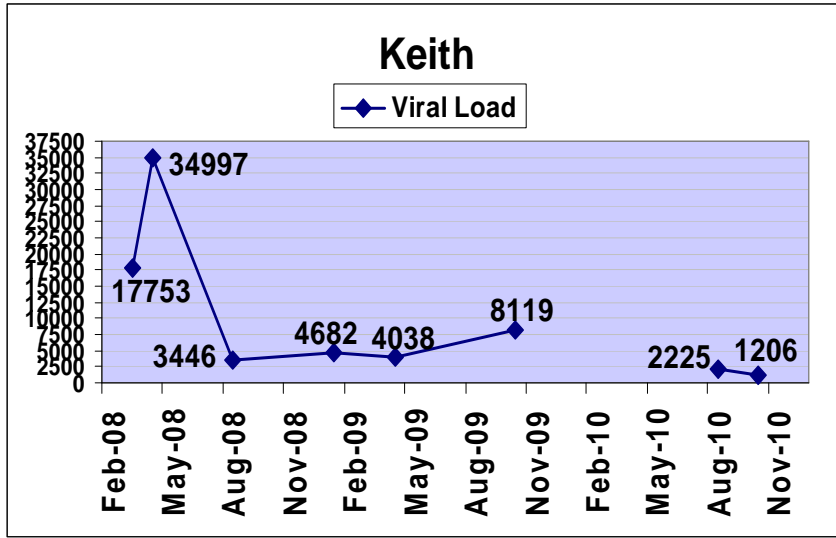
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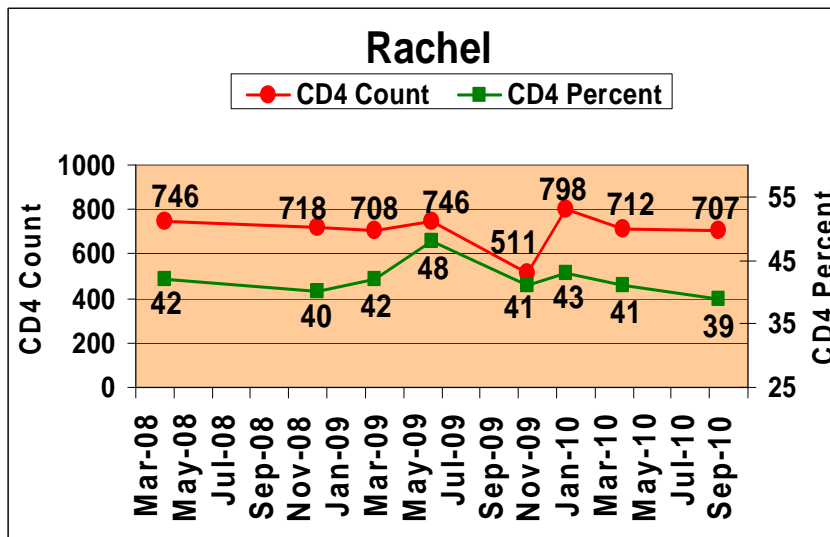
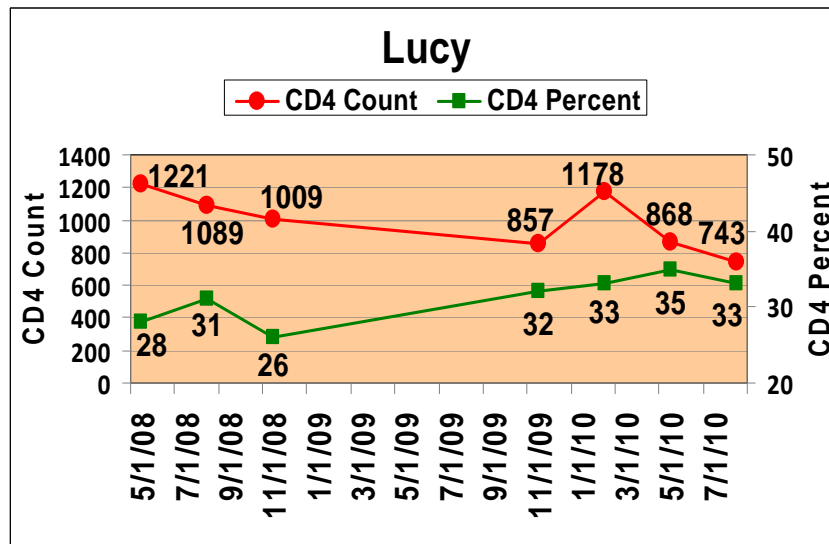
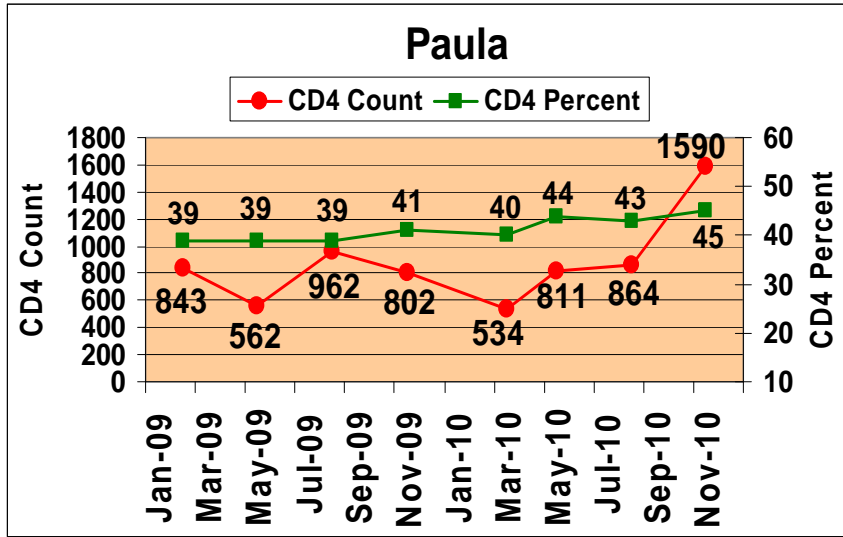
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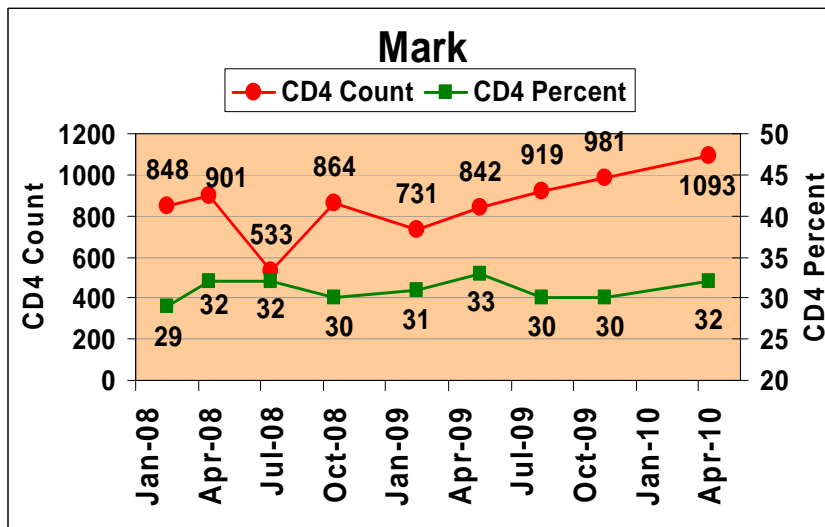
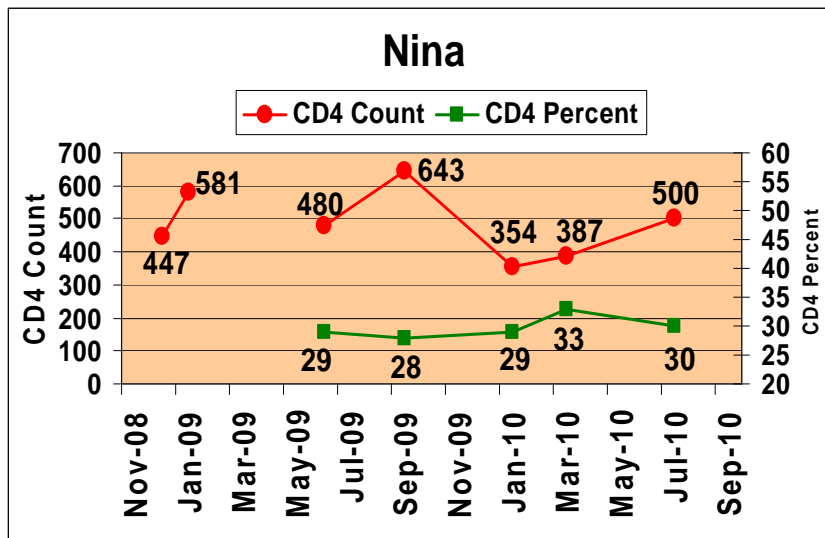
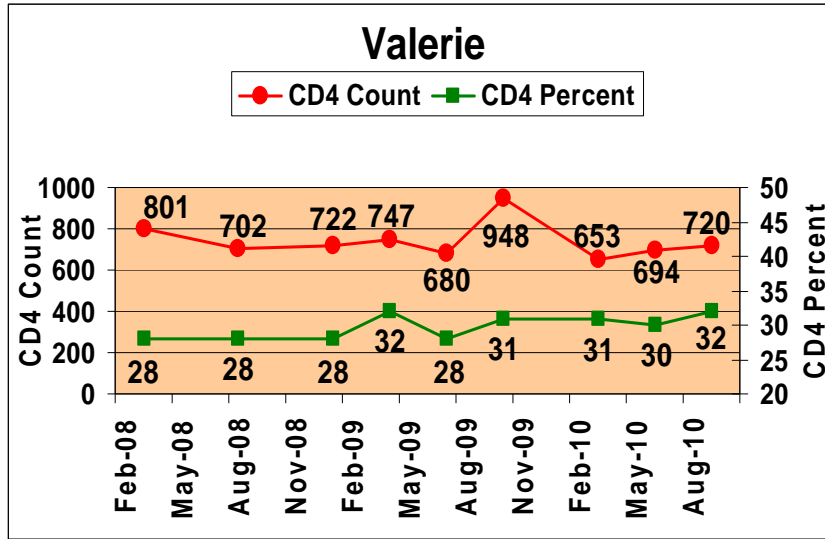
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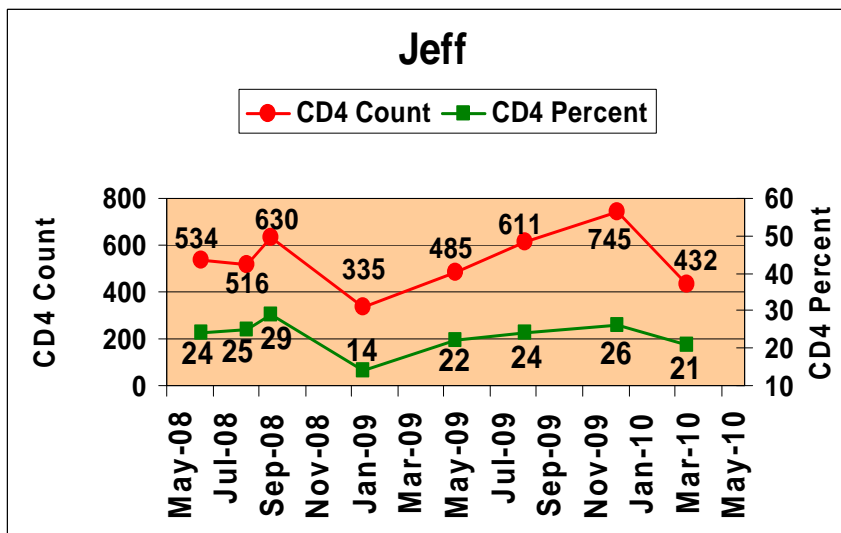
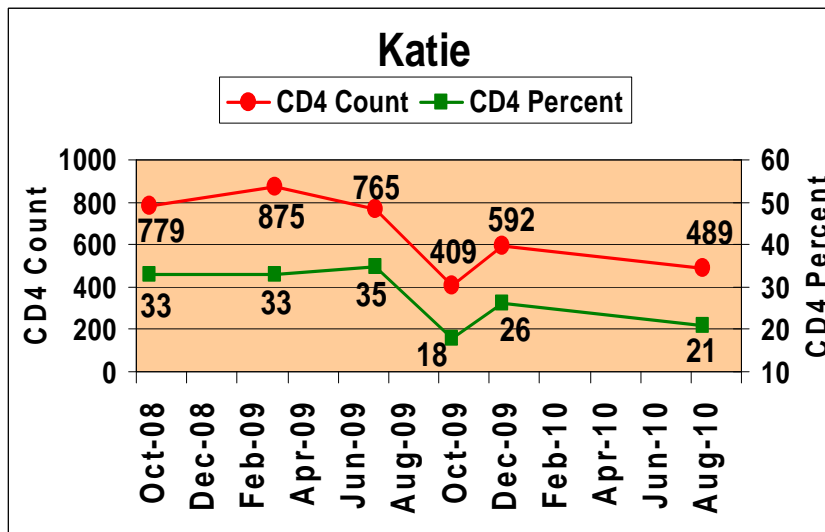
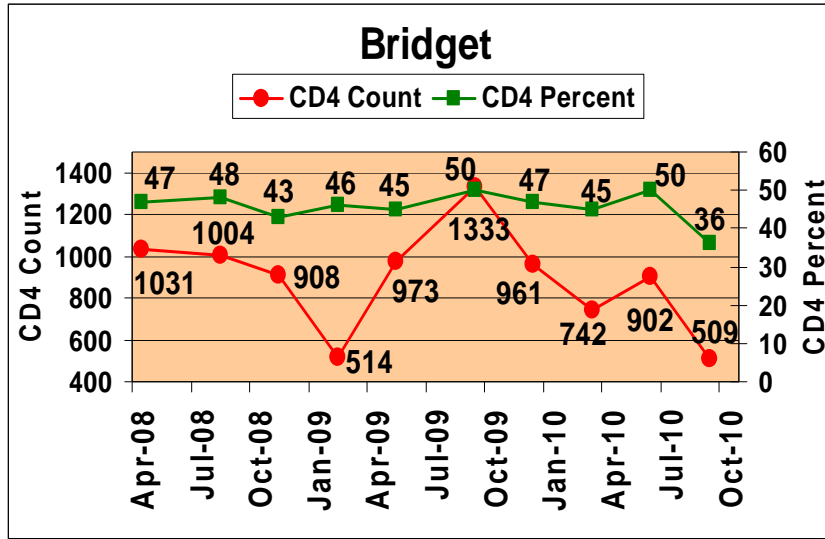
Appendix G: Graphs of Adolescent CD4 Counts/Percents



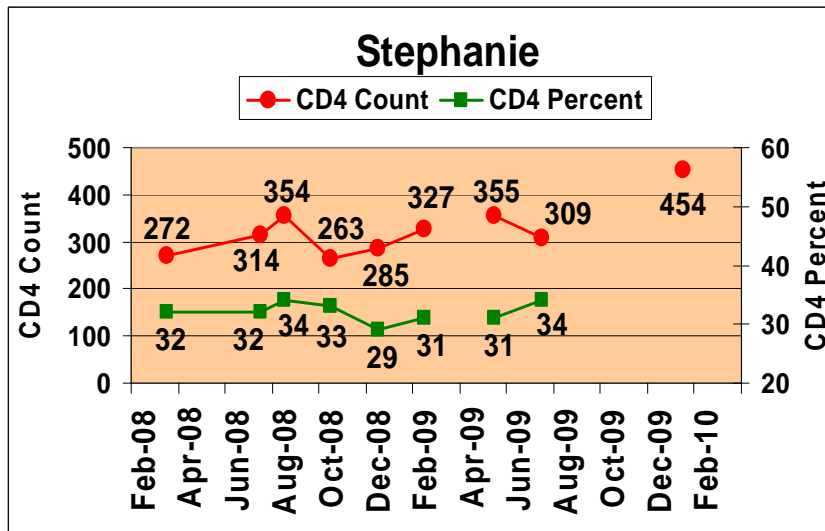
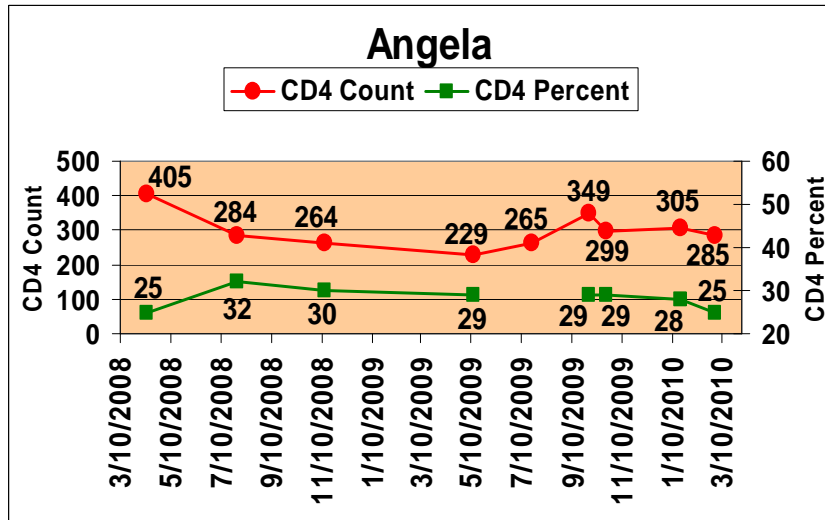
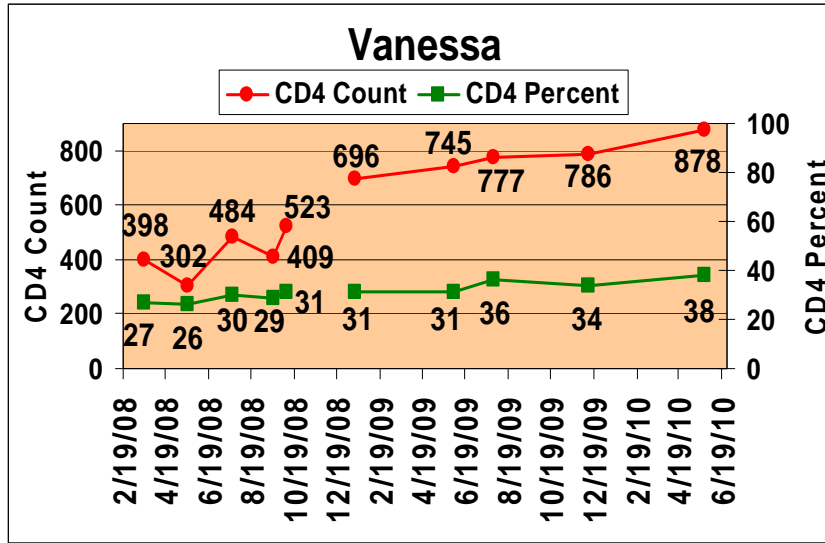
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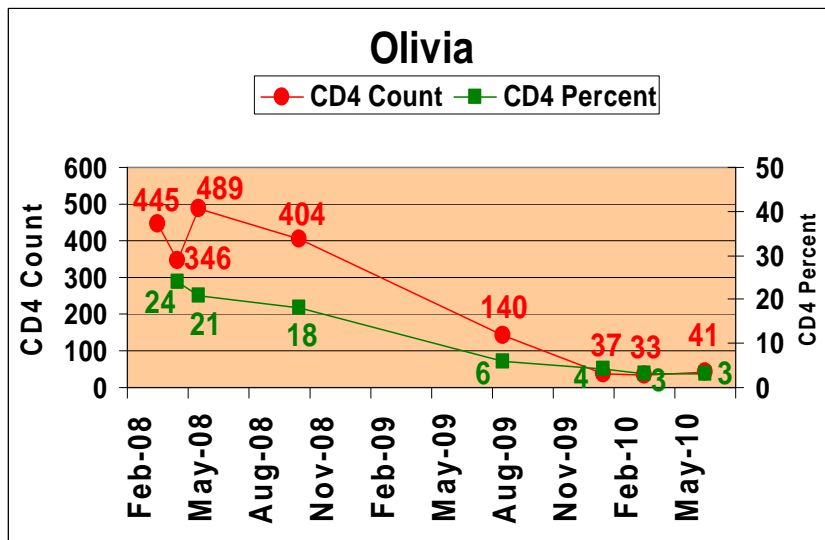
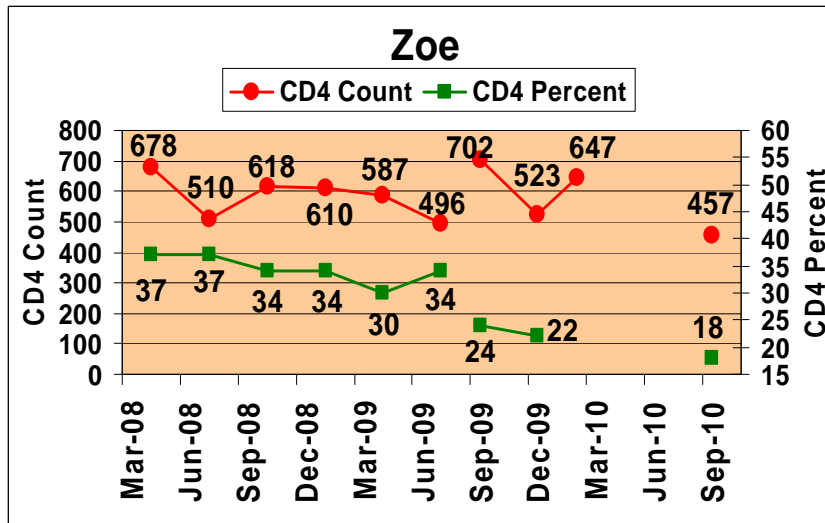
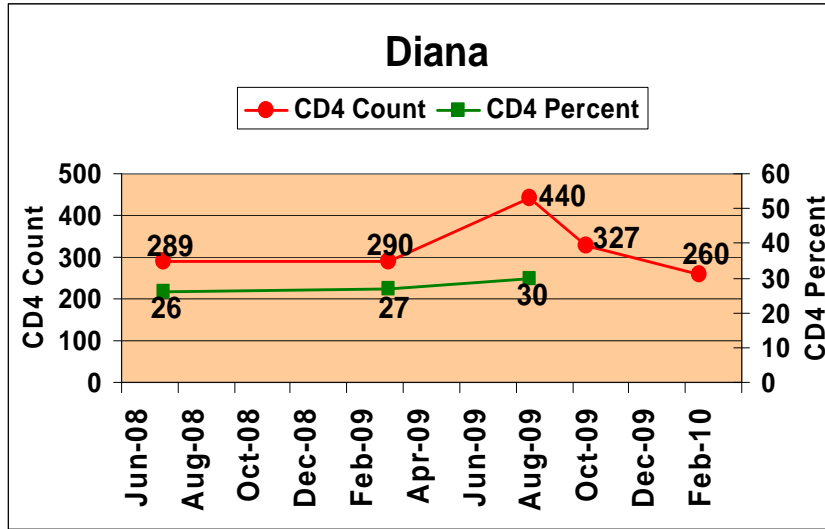
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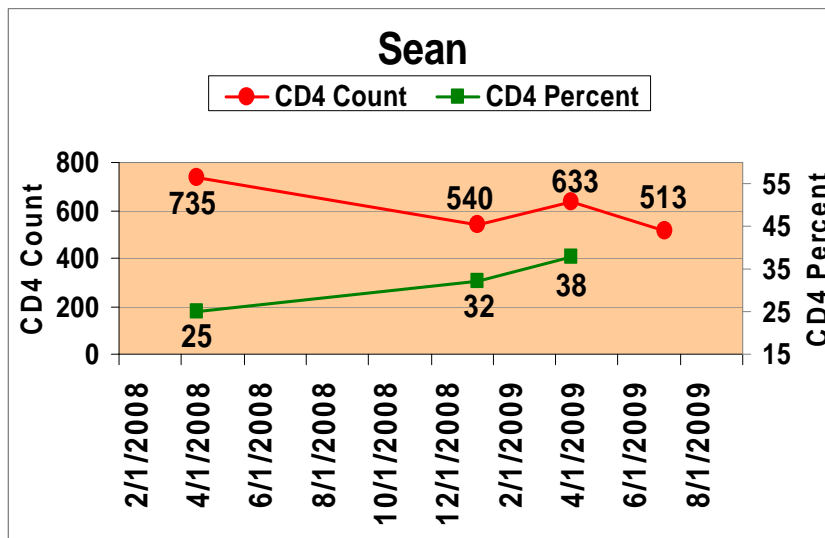
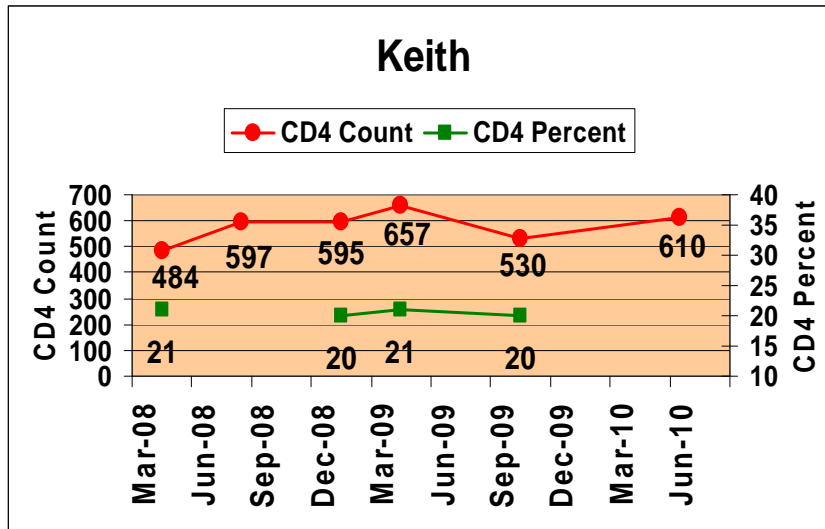
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Appendix G: (Continued)



Appendix G: (Continued)



ABOUT THE AUTHOR

Barbara Szelag earned a Master's Degree in African Studies and a Master's Degree in Public Health from UCLA, and a Bachelor's Degree in Biology from Vassar College. She was a Peace Corps Volunteer in Benin from 1980 to 1982, where she taught high school biology in Aplahoué. She also taught English as a Second Language from 1989 to 1993 at the American Cultural Center in Lomé, Togo. Since 2001, she has been the Data Quality Manager and Quality Management Coordinator for the Florida Family AIDS Network, a Ryan White, Part D-funded program that provides clinical and social support services to HIV-infected and affected women, infants, children, youth, and families in the Tampa Bay area.