Institute for Clinical Social Work

ATTACHMENT, DEPRESSION, AND MEDICATION IN ADOLESCENTS WITH HIV INFECTION

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ABSTRACT

The medicine that kept infants born with HIV alive for years is now threatening their existence in adolescence. Antiretroviral medications decrease in efficacy and boost the virus if not taken nearly perfectly. Attachment issues are rampant in these adolescents due to maternal depression, addiction, and death. Attachment trauma contributes to depression and depression prompts non-adherence.

Using a mixed methodology approach this study analyzed adherence, attachment histories, and level of depression in a randomly selected sample population of 20 perinatally HIV infected adolescents ages 14 to 18. The limitation of this study was its small sample size.

A statistically significant relationship between depression and adherence exists *t=-2.103, p=.05. The psychopathology that emerged from early attachment trauma substantially impacted the subjects' current ability to trust the medicines and medical team. Conversely, adherent subjects had a secure attachment style, as indicated by their caregiver/child's early attributions and shared memories.

This population would benefit from participation in psychotherapy to address early trauma. Also, the medical team can circumvent the defensiveness of the caregiver/ child dyad by interpreting the unconscious message they are conveying through their non-adherence. The experience of empathy may allow them to trust the medical team and medicines.

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EL

TABLE OF CONTENTS

Page

ABSTRACT……...ii

ACKNOWLEDGEMENTS...……iii

LIST OF TABLES..……....v

Chapter

I. INTRODUCTION……1
History of Problem
Problem Formation

II. LITERATURE REVIEW…….....…4
Overview of the Literature
Theoretical and Conceptual Framework
Definitions
Assumptions

III. METHODOLOGY…….....……26
Sample Selection
Instrumentation
Data Management and Analysis

IV. RESULTS …….....……31
Description of the Sample, Quantitative Data, and Qualitative Data
Findings

V. DISCUSSION AND CONCLUSIONS…….....….85
Depression
Attachment
Conclusion

TABLE OF CONTENTS—*Continued*

Appendixes

A. PACTG 219C PEDIATRIC ADHERENCE QUESTIONNAIRE.....105

B. SEMI-STRUCTURED QUALITITATIVE INTERVIEW WITH CARETAKER.....109

C. SEMI-STRUCTURED QUALITIAVTIVE INTERVIEW WITH THE ADOLESCENT.....111

D. INVENTORY OF PARENT AND PEER ATTACHMENT (IPPA).....114

E. BDI–II.....118

REFERENCES.....121

LIST OF TABLES

Table Pages

1. Demographics of Population.....……....30
2. Age of Subjects in Population…...……30
3. Deceased Birth Parents and Lost Siblings…….……31
4. Mode of Transmission……..…….32
5. Age of Attachment Disruption and Placement…..…….33
6. Current Placements…....……34
7. Attachment Styles…...……39
8. Maternal Attachment Scores……...……43
9. Securely Attached to Maternal Caregiver…….....…….44
10. Insecure Attachment to Maternal Caregiver……..…….48
11. Paternal Attachment Scores……...…….50
12. Attachment to Peers…….....……52

CHAPTER I

INTRODUCTION

Thirty years ago the human-immune-deficiency virus was discovered in the human body. HIV/AIDS was a violent disease which quickly dismantled the human immune system. Although the prognosis for infants born with HIV was three to five years, many of these infants survived into adolescence. Currently, non-adherence to medications threatens their continued existence, and is a pervasive and complicated problem which requires a deeper understanding. This study pursues an explanation of how the facets of attachment, depression, and development coalesce to influence adherence.

History of the Problem

As the first generation of children infected with HIV alive today, and against all predictions, infants born with HIV have reached adolescence and young adulthood. Although other chronically ill children have survived into adolescence, no other population shares the issues that impact this population's mental and physical survival.

For example, as a whole, this population endured maternal and paternal death, depression, substance abuse, and a fatal illness tainted with a shameful stigma. Unlike children with other illnesses, this population was treated unsympathetically because of fear and prejudice. In addition, the knowledge that their own parent was the catalyst for their illness differentiates them from other chronically ill children. Due to medical

technology, this population has miraculously survived. Today, the medicines that once kept this population alive are quickly becoming ineffective.

Formulation of the Problem

The purpose of this investigation was to examine the relationship between the qualities of attachment, depression and medication adherence in adolescents with HIV-1 infection. Early disruptions in attachment relationships are significantly correlated with depression among adolescents with perinatally acquired HIV infection. Attachment relationship disruptions and depression are significantly related to high rates of non-adherence to antiretroviral medication regimens during adolescence.

The quality of attachment relationships, symptoms of depression, and medication adherence of 20 adolescents, ages 14-18 years, were evaluated. Family history, demographic information, and health information were examined. Psychological factors which were related to medication adherence and non-adherence were identified and analyzed in order to derive an understanding of the dynamics that deter an adolescent from adherence.

With the advent of highly active antiretroviral therapy (HAART), children with HIV infection/AIDS are surviving into adolescence and early adulthood in large numbers. Clinical reports from U.S. medical centers indicate substantial mental health and behavioral problems among adolescents with HIV infection, including depression and perceived medication non-adherence. Non-adherence threatens to extinguish a population that has been kept alive by medical technology. It is the psychological component, or meaning that is attached to these medicines, that must be explored and

understood, if these adolescents are to survive. This work will significantly improve our understanding of the mental health functioning and behavior of adolescents with HIV-1 infection and will promote the design and implementation of more sensitive and individualized mental health and adherence interventions that will, potentially, save lives.

Adolescents with perinatal HIV infection are at high risk for mental health problems and poor medication adherence due to a confluence of disease-related, genetic, and environmental factors. These include but are not limited to progression of HIV disease, neurocognitive deficits, family histories of substance abuse and psychiatric illness, and development in the context of poverty and limited resources. The etiology of mental health and behavioral problems may also include discontinuities in attachment relationships, which are not uncommon among children with HIV infection. The impact of early histories of separation, loss and trauma on the quality of attachment relationships in adolescents with HIV infection has not been fully explored, nor has the effect of attachment disruptions upon the development of depression, a known risk factor for poor adherence.

CHAPTER II

LITERATURE REVIEW

Recently, a great deal of research has indicated that adolescents with HIV infection, and perinatal HIV infection, are poorly adherent to their medications. The first generation of children born with HIV-1 infection is surviving into adolescence and young adulthood. Due to the demanding nature of highly active antiretroviral medication regimens, imperfect adherence behaviors cause many adolescents to be at risk for virologic and immunological failure (Van Dyke et al., 2000; Murphy et al., 2001; Dolezal, Mellins, Brackis-Cott & Abrams, 2003; Mellins et al., 2003; Steele & Grauer, 2003).

In a convenience sample of adolescents at a large urban pediatric hospital, 83 % of adolescents displayed current or recent adherence difficulties (Malee et al., 2004). High rates of non-adherence are observed among adolescents at other large urban medical centers as well (Hosek, Domanico & Harper, 2002; Murphy et al., 2001; Murphy et al., 2003).

Recent findings of an investigation of long-term outcomes in children with HIV infection (PACTG 219C) indicate that successful adherence declines with increasing age (Malee et al., 2004). In addition, delays or impairment in cognitive, language, memory and self-regulatory functioning, which are common among children with HIV infection (Chase et al., 2000; Mellins, Levenson, Zawadzki, Kairam & Weston, 1994; Wolters,

Brouwers, Moss & Pizzo, 1995; Blanchette, Smith, King, Fernandea-Penney & Read, 2002) may interfere with an adolescent's ability to take her medication systematically and independently. Twenty-seven percent of PACTG 219C participants, ages 3-18 years, have been diagnosed with at least one neurological or psychiatric disorder and 34% require special educational services in school (Malee et al., 2004).

The literature indicates that developmental issues play a role in non-adherence. Normal developmental issues in adolescence, such as the struggle for independence, an exaggerated sense of immortality and invulnerability, the desire to question authority, and the need to identify with one's peers propel adolescents towards non-adherence (Elliott, 2001; Malee et al., 2004). The hallmarks of adolescent psychosocial development include; rebellion, opposition, manipulation, and forgetfulness. These are "symptoms" of the separation and individuation process, which is the primary developmental task for the adolescent (Rothenberg, 1990).

The task of individuation and separation is motivated by the adolescent's new cognitive capacities for complex abstract thought. Adolescents are interested and able to formulate their own ideas and opinions on issues that they had previously and unassumingly adapted from their caretakers (Rothenberg, 1990). Often adolescents want to do things their own way, or think about things in their own way, which motivates them to question the authority of doctors and caretakers. Physicians and nurses represent authority figures, and adolescents take a certain pride or joy in not doing what the doctor or nurse tells them to do (Elliott, 2001). Frequently, adolescents reject parental and authoritative dictates, such as taking medicines, by adopting opposite view points and behaviors in an effort to establish their autonomy (Rothenberg, 1990; Elliott, 2001).

Also, taking risks is a normal facet of the individuation process. Feelings of grandiosity and omnipotence frequently fuel risk-taking behaviors. These feelings are also consistent with the denial of mortality (Rothenberg, 1990). An exaggerated sense of immortality allows adolescents to feel invincible, and consequently, less likely to take their medications (Elliott, 2001).

Peer influences and peer acceptance become critically important as the adolescent moves away from the family. A feeling of likeness bolsters self esteem and self confidence, so adolescents become slavishly conformist to their peers, and seek constant approval. They feel compelled to connect with their peers, to join groups, and to participate in group activities (Rothenberg, 1990). Often they spend hours on the phone or on the computer fostering this connection. The odds are good, however, that members of their peer group, especially the ones who tend to be most admired, don't require medication everyday. Constrained by daily multiple doses of heavy medicines with unpleasant side effects, adolescents infected with HIV must follow a different routine. Quite often they choose fitting in with their peers over taking medicines (Elliott, 2001). Taking medications means having an understanding of oneself as a patient, and thus, dependent. This self identification is in direct conflict with a normal adolescent's struggle for independence.

Physical and sexual development are integral aspects of normal adolescent development, yet are additionally complicated for HIV infected adolescents. The internal stress of hormonal eruptions, explosive physical growth, sexual maturation, and sexual curiosity, challenge an adolescent's ability to feel self assured. Physical appearance and attractiveness become a preoccupation for all adolescents (Davies, 1999). These new

fascinations are particularly problematic for adolescents with HIV infection, many of whom have body lipodystrophy due to antiretroviral therapy regimens that incorporate a protease inhibitor. Adolescents with HIV infection also have the additional burden of having to be prepared to disclose their diagnosis to a potential sexual partner.

In addition to normative developmental challenges, adolescents who were born with HIV infection have had an additional set of developmental complications and considerations. Once referred to as the "AIDS babies," they were predicted to live only a couple of years if they were lucky. No one talked about their future dreams and aspirations because they were not thought possible or realistic (Dee, 2005). Their disease had a stigma and was associated with suffering and death.

Often, their own parents embodied this stigma of shame, suffering and death; particularly when they had to face the fact that they infected their child with the virus. Eventually, the child was also faced with the knowledge that this loved, needed parent had infected them with the same virus, and potentially a similar fate. This certainly colored the way these children were related to by caregivers, relatives, and friends (Malee et al., 2004).

Every juncture of their development, including their attachment relationships, has the stigma of a terrifying and life threatening disease which caused others to be frightened for them and of them (Malee et al., 2004). Therefore, maturation becomes associated with sickness and death, rather than aspirations and the excitement of possibility in an adult world.

Adolescence, more then any other stage in human development, generates vulnerability for depression. The strife associated with normal adolescence compounded

by the anxiety of a life threatening and stigmatizing disease leads to significant escalation of psychological distress in adolescence (Rabkin & Chesney, 1999). In fact, the literature indicates the risk for childhood depression is three times greater if an early loss is combined with a child's own life threatening occurrences, long-term troubles, or problematic personal relationships (Greenberg, Cicchetti, & Cummings, 1990).

Adolescents with HIV infection are at great risk for depression, a known catalyst for poor adherence (Hosek et al., 2002; Rabkin & Chesney, 1999; Starace et al., 2002). Depression is a significant predictor of medication non-adherence in HIV-infected adolescents (Hosek et al., 2000). Half of the HIV infected adolescents studied in the United States are poorly adherent to their prescribed medications, with complexity of the regimen and depression playing substantial roles in non-compliance (Murphy et al., 2003).

Adolescents with HIV infection may have limited or ineffective family support as they struggle with achieving the goal of full medication adherence. Family histories of substance abuse and psychiatric illness are common among adolescents with HIV infection (Mellins, Brackis-Cott, Dolezal & Meyer-Bahlburg, 2005) and may significantly impact the quality and consistency of care giving and guidance regarding medication management, and the child's risk for depression.

Additionally, the risk for depression increases dramatically if a childhood loss interfaces with life threatening events, enduring problems, or stressful home environments (Greenberg, Cicchetti & Cummings, 1990). Many perinatally HIV infected adolescents have experienced the loss of one or both parents to HIV/AIDS and have experienced the challenge of multiple caretaking transitions, including foster care

placement and/or extended family care. In addition, the majority of HIV infected adolescents live in large urban environments and may be confronted with high levels of daily life stress, secondary to poverty and limited resources in inner-city communities (Mellins et al., 2003).

These losses and transitions would increase stress on anyone. The additional stress associated with one's own chronic illness as well as unique factors specific to HIV/AIDS further contribute to the risk for depression. For example, according to the research, maternal depression and a stigmatizing, life-threatening chronic illness increase an adolescent's risk for depression threefold (Greenberg, Cicchetti & Cummings, 1990; Dulcan, Martini & Lake, 2004). Maternal death before the child reaches the age of 11, the absence of an adequate caregiver after the loss of the mother, and family conflict also contribute to the risk for depression (Parkes et al., 1991; Armsden & Greenberg, 1987; Greenberg et al., 1990) and are not uncommon among children with HIV infection/AIDS.

Attachment disruptions during the first three years of life, whether related to maternal illness, separation, death, substance abuse, psychiatric illness, physical or emotional abuse or neglect or other factors, not only increases the child's vulnerability to depression but detract from the child's self esteem and ability to trust and ask for help in interpersonal relationships (Lebelle, 2000; Armsden & Greenberg, 1987; Parkes et al., 1991; Greenberg et al., 1990). Deficits such as these, contribute to the development of defenses that impact the ability of the child to both attain and sustain positive adherence behaviors and place them at increased risk for psychological illness in adolescence (Greenberg et al., 1990).

Attachment disruptions can impede ongoing psychological development and create psychopathology throughout the life course (Bradley, 2000; Rothenberg, 1990). The most severe attachment disruptions include the death of a child's mother, maternal depression, sudden maternal separation, and the absence of an adequate and affectionate caregiver after the loss of a mother (Lebelle, 2000; Parkes et al., 1991; Cicchetti, Rogosch, & Toth, 1996).

The probability that perinatally HIV infected adolescents experienced exacerbated attachment difficulties in their teens is likely due to their experience of early attachment disruptions. These disruptions include traumatic loss and separations from a parent. Often these losses and separations were caused by maternal death, maternal substance abuse, and maternal clinical depression (Mellins, Smith, O'Driscoll, Magde, Brouwers, Chase, Blasini, Hittleman, Llorente, Matzen, 2003).

A high prevalence of noninjection substance abuse, psychiatric disorders, and chronic stress has been found in the birth mothers of HIV infected children (Mellins et al., 2003). 52% of perinatally infected children who have AIDS were born to women whose risk factor for HIV is their own intravenous drug use (Mellins et al.,2003).

Thirty percent of the perinatally infected adolescents seen at the hospital have lost their biological mothers to HIV. Many of the adolescents who lost their mothers to HIV were placed in foster care or relative care at an early age. The quality of the care they received following their mother's death has not been studied, but is crucial in understanding their attachment difficulties as adolescents.

The prototypical attachment relationship is the relationship between the primary caregiver and infant. The development of trust in infancy is not only the foundation from

which every human being operates in relationships, but it is also the foundation from which future developmental tasks evolve (Ainsworth, Blehar, Waters, & Wall, 1978). The attachment relationship is crucial in impacting the way in which affect, cognition, and behavior are organized (Ainsworth, Blehar, Waters, & Wall, 1978).

Attachment has a biologic base, and the infant's attachment behavior has the aim of maintaining physical proximity to their caretaker in order to sustain a sense of security (Davies, 1999). There are four essential purposes for attachment: providing a sense of security, regulation of affect and arousal, promoting the expression of feelings and communication, and serving as a base for exploration (Davies, 1999).

The establishment of an attachment relationship with the primary caregiver during the first year of life is an essential accomplishment which organizes evolving affect, cognition, and behavior in relation to the quality of physical and emotional accessibility and responsiveness of the caregiver (Cicchetti & Toth, 1998).

The child progressively internalizes a working model of attachment shaped by the care he has received (Bowlby, 1973; Davies, 1999). Over the first few years of life, working models of attachment become constant and unconscious expectations of what can be anticipated from other people, and of how relationships work (Davies, 1999). Simultaneously, models of the self in the context of this relationship develop. The child internalizes suppositions abut how worthy of care and how valued he is (Bowlby, 1973; Davies, 1999). The core component of working models is a perception of the self within relationships, which robustly contributes to the child's self representation, self esteem, and overall psychological health (Bowlby, 1973; Davies, 1999).

For instance, infants who have experienced intense affect and stress without the intervention of a soothing caretaker, are prone to internalize a perception of the self as out of control (Davies, 1999). If the caretakers are preoccupied and overwhelmed with depression, they do not respond to the infant's distress signal. In consequence, an infant cannot obtain assistance in regulating affects and is likely to withdraw (Tronick & Gianino, 1986; Davies, 1999).

Maladaptive coping strategies and depression habitually arise in these infants (Davies, 1999). They experience aberrant affective interchanges that support divergences in their early affect development. These early affect divergences provide momentum for a budding depressive disorder (Ciccheti & Toth 1998).

Recent research on attachment disorders strongly support the claim that caregiver depression is strongly correlated with the infant's development of an insecure attachment style and childhood depression. A caregiver's continued psychological unavailability due to depression is strongly linked with the development of an insecure attachment in the child (Bowlby, 1988; Davies, 1999; Ciccheti & Toth, 1998). The child of an emotionally unavailable parent, especially if the parent was unavailable when that child was young, is likely to develop working models that are consistent with depression (Bowlby, 1988; Davies, 1999; Ciccheti & Toth, 1998).

According to recent research findings, the implications of early attachment difficulties in adolescence are profound. In early adolescence, teenagers who expressed insecure attachments to their parents were more often evaluated as clinically depressed, as compared with normal or nondepressed teenagers (Armsden, McCauley, Greenberg, Burke, & Mitchell, 1991). Among early to middle adolescents, deficits in parent

attachment and peer attachment, were associated with hopelessness and an externally oriented locus of control (Armsden et al., 1987; Lewis et al., 1987).

In late adolescence, an insecure attachment organization can result in depressive symptomatology and increased interpersonal difficulties (Kobak, Sudler, & Gamble, 1991). Normally, in late adolescence, parent and peer attachments correlate with positiveness and stability of self-esteem, life-satisfaction, and affective status, as opposed to the overwhelming feelings of depression, anxiety, resentment/alienation, covert anger, and loneliness, to which these adolescents are prone (Armsden & Greenberg, 1987; Armsden, 1986).

The relationship between attachment and affective organization holds even when the number of negative life changes are controlled (Armsden & Greenberg, 1987). In adolescence, the quality of attachment to parents is associated with self-reported tendencies toward the use of more problem-solving and coping strategies relative to emotion-managing efforts in stressful situations (Armsden, 1986).

Unresponsive and unpredictable attachment relationships cause anxiety, sadness, anger, and depression in adolescence (Rothenberg, 1999; Bradley, 2000; Armsden & Greenberg 1987). Developmental lags, low self esteem, and deficient interpersonal relationships throughout adolescence are often the outcome of early attachment disruptions (Armsden and Greenberg 1987; Greenberg et al.,1990). Lack of early quality of parental care can result in a cognitive structure in adolescence that is characterized by a sense of helplessness and low self esteem. Yet, adolescence is the time when establishing a foundation of self reliance is paramount (Armsden and Greenberg 1987;

Greenberg et al.,1990). Internalized working models of attachment figures are integral to the adolescent's ability to separate and individuate (Greenberg et al., 1990).

There is also a strong link between an adolescent's attachment relationships and their ability to take care of themselves and take an active interest in their physical health. Self-reliance and the ability to seek help are attributes of an adolescent with a good attachment style. The child and adolescent with an unhealthy attachment style is unable to trust in another and ask for help in times of need (Armsden et al., 1987). Asking for help and taking responsibility for medicines is an essential part of adolescent healthcare.

Overall, HIV infected adolescents who experience attachment difficulties are less equipped to master difficult age appropriate tasks, like medicine management. The quality of life at early ages is important not only in immediate well being, but also for health and development throughout adolescence and adulthood (World health Organization, 2003). The probability that this population experienced some sort of attachment disruption combined with this population's vulnerability to hopelessness and depression leaves them at great risk.

Unfortunately, no recent studies in clinical social work have explored the relationship between early attachment disruptions, depression and medication adherence in adolescents with HIV infection. This investigation addresses these issues and may ultimately inform the process by which mental health services and adherence counseling are delivered to adolescents and families affected by HIV/AIDS.

Theoretical and Conceptual Framework

The theoretical and conceptual framework used to support this study originates from two theories: The developmental component of Object Relations Theory, and Attachment Theory. Both theories contribute to a complex explanation of the bio-psychosocial context, and the multiple psychological factors which influence an adolescent's ability to take their medications consistently.

According to psychosocial theory, there are many innate characteristics with which a child comes into this world. These characteristics, abilities, and new capacities develop and grow from the child's experience of relationships. These relationships inspire and challenge a child to continue exploring and challenging himself. Current developmental successes are built upon prior developmental masteries (Bradley, 2000).

From an object relations perspective, the normal psychosocial developmental tasks of adolescence include: separation and individuation, identity formation, the expansion and deepening of peer relationship, and moral development (Greenspan & Pollock, 1980). Some researchers identify the separation and individuation phase as the most important task of adolescent development. It is critical because it encompasses the final thrust towards autonomy (Rothenberg, 1990). The challenge of separating and individuating includes the adolescents' struggle for independence from their parents. Often, this is referred to as the second individuation phase and is a recapitulation of the first three years of life (Blos, 1967).

Adolescents develop cognitive capacities which enable them to think about things in new and more complicated ways. In contrast to young children, adolescents have the cognitive capacity to interpret social and cultural norms, reflect on the past, and to

contemplate the future (Spencer & Dornbusch 1998). These new developmental capacities may be painful for a perinatally HIV infected adolescent, as their biological mothers transferred the virus to them in the past, impacting their lives in the present and in the future. The reflection on the past requires the onerous task of integrating this insult and coping with the residual feelings of ambivalence and confusion.

There is both immense pleasure and intense conflict in a healthy adolescents' realization that they have the ability to think about life for themselves. Because of this conflict the adolescent sometimes has the tendency to "overshoot" the mark and become rebellious. Adolescents routinely reject parental dictates and values by embracing opposite view points and corresponding behaviors in order to gain autonomy (Rothenberg, 1990). Parents often interpret this as rejection and feel distant from their adolescent during this time. Adolescents are often perceived as experimental and rebellious with an exaggerated sense of immortality (Greenspan & Pollock, 1980). This inflated sense of immortality and an inherently rebellious attitude deter an adolescent from taking their medicines.

For all adolescents, feelings of grandiosity and omnipotence often compel risk-taking behaviors and, therefore, experimentation is a normal part of the individuation process (Rothenberg 1990). Adolescents infected with HIV experience an exaggerated sense of invincibility in defense against constant confrontation with their vulnerability. Unfortunately, this defense masks their awareness of the need to take medications during this phase (Elliott, 2001).

The second developmental task of adolescence is identity formation. Identity formation is a conscious sense of individual uniqueness while maintaining the cohesion

of a group's ideals (Spencer & Dornbusch, 1998, Rothenberg, 1990). This is a crucial stage for the adolescent because they are trying to figure out who they are in the context of the larger world. The adolescent is discovering and embracing their gifts and their interests. Often they pursue athletics, music, art, or activities that appeal to them.

In school they begin to choose career paths and make decisions about their future lives. For perinatally HIV infected adolescents, this task is complicated by a lifelong illness. Many of these adolescents have internalized the identification of a "sick child." Feeling empowered or hopeful is unfamiliar to them. Due to illnesses and the stigma of HIV, many of them have been excluded from participating in the activities their healthy peers participate in, and these peer group activities often play an immense role in the identity formation process.

During adolescence, most turn progressively toward their peers, which is the third developmental challenge of adolescence (Spencer & Dornbusch, 1998). Adolescents become slavishly conformist to their peers' dictates. They seek approval from peers and continually feel the need to connect with them, to join groups, and to be included in activities (Rothenberg, 1990). This is difficult for a perinatally HIV infected adolescent who is tied to a strict and unforgiving medicine routine, multiple doctors visits, and who is perceived as different by the general peer group.

According to their activities and interests, adolescents often select a peer group with whom to spend time. This is difficult for an adolescent infected with HIV, as many of these adolescents choose to keep their illness a secret from their peers. Their "secret keeping" is often the result of familial pressure, set forth to prevent the adolescent from experiencing prejudice outside of the family. Often, keeping this secret leaves the

adolescent feeling unconnected with people outside of the family, and deters the adolescent from experiencing close relationships with their peers. Healthy adolescents, on the other hand, are spending more time with their friends, and less time with their parents and families. This leads to deeper friendships and the beginning of the dating process (Rothenberg, 1990). For an adolescent infected with HIV, disclosing their diagnosis is not only risking rejection from their friends and peer group, but also by potential dating partners. Thus, the conflict between initiating close relationships by being able to be who they are, and risking the rejection that may ensue, is a difficult one preventing them from feeling a true sense of inclusion in a group. The intense desire for intimacy in friendships is frustrated, as it is thwarted by the urgency of keeping the secret. This results in the adolescent feeling isolated and depressed.

The peer group also influences the adolescent's ideas about values and judgments. In collaboration with individuation and identity formation adolescents develop their own ideas about morality, which is the last developmental mission of adolescence. They often question religion or develop their own ideas about spirituality. They sometimes question humanity and social justice. Frequently, they will rebel against general societal values in order to express themselves. Adolescents who suffer from life threatening illnesses, depression, and attachment disorders often have more difficulty sorting out their ideas about morality (Rothenberg, 1990).

Like developmental theory, attachment theory includes imperative information about adolescents and adolescent behavior. John Bowlby developed the original attachment theory from his observations of young children when separated from their parents. He theorized that infants had a biological instinct to maintain close proximity

with their caregiver (Bradley, 2000). Infants maintained the desired closeness by initiating behaviors which attracted and sustained their caregiver's attention. These behaviors included, crying, cooing, smiling, and maintaining strong eye contact with their caregiver (Bradley 2000, Davies 1999).

Caregivers in healthy attachment relationships are able to read their infants communications and respond to them appropriately, allowing an infant to develop a sense of security. With this sense of security, the infant, when developmentally capable, can move away from the caregiver to explore the environment while using the caretaker as a secure base. The child internalizes the reliability and consistency of the caregiver, and constructs an internal working model or schemata (Bradley, 2000).

Mary Ainsworth developed a system to measure the quality of the attachment relationship called The Strange Situation. A three pronged classification system for the parent-child attachment was the outgrowth of this procedure (Bradley, 2000). The first classification is the secure attachment which is marked by the child feeling generally positive in the presence of their main caregiver, showing distress at separation, and showing relief when reunited with the caregiver.

In contrast, the second classification, the insecure attachment, also classified as resistant and avoidant, is defined by child's negative emotional stance towards their caregiver and their caregiver's attempts to engage the child after a separation. The child cannot be soothed by the caregiver and continues to be upset (Bradley, 2000).

The third classification, disorganized/disoriented attachment style is the most pathological attachment style, and is often characterized by the child withdrawing from their caregiver and environment. Sudden and traumatic separations from a child's

caregiver are called attachment disruptions. Often, attachment disruptions can impede ongoing psychological development and create psychopathology throughout the life course (Bradley, 2000). It is this experience that this research will be focused on.

The core assertion of attachment theory is that children form internal working models of themselves in relation to others. These models primarily exist outside of consciousness but dictate behavior in new relationships (Rothenberg, 1990).

According to attachment theory, attachment disruptions impact an adolescent's developmental capacities, psychological well-being, and interpersonal relationships. Low self esteem, developmental lags, and poor interpersonal relationships throughout the lifespan are also the consequence of early attachment disruptions. In regard to a child's psychological development, working models of attachment figures continue to form in early childhood and serve to maintain an individual's developmental pathway throughout adolescence (Greenberg et al., 1990).

There is a strong link between an adolescent's attachment relationships and outcomes like self-concept, psychological adjustment, and physical health. An adolescent with a secure attachment style is more likely to balance self-reliance and appropriate help seeking capacities as he matures. An adolescent with an unhealthy attachment style is unable to trust in another and ask for help in times of need (Armsden et al.,1987).

Attachment disruptions impede ongoing psychological development and create psychopathology throughout the life course (Bradley, 2000; Rothenberg, 1990). The most severe attachment disruptions include the death of a child's mother, maternal depression,

sudden maternal separation, and the absence of an adequate and affectionate caregiver after the loss of a mother (Lebelle, 2000; Parkes et al., 1991; Cicchetti et al., 1996).

The probability that perinatally HIV infected adolescents experience attachment difficulties in their teens is likely due to their experience of early attachment disruptions. These losses and separations were caused by maternal death, maternal substance abuse, and maternal clinical depression (Mellins et al., 2003). The relationship between attachment disruptions, depression, and medicine adherence in adolescents with HIV infection must be explored. Thus, the research question asked in this study is: do early disruptions in attachment relationships and depression play a major role in medication adherence among adolescents with perinatally acquired HIV-1 infection?

Definitions

Acquired Immune Deficiency Syndrome (AIDS): The most severe form of HIV infection and occurs when the immune system has been dismantled by the virus and the virus is causing opportunistic infections in the body such as, PCP, MAC, LIP, encephalopathy, and wasting.

Adherence (medical): The ability of a patient to remain compliant with medical appointments, medications, and recommendations.

Antiretroviral: A drug that can help slow the progress of HIV disease in some people.

Antiretrotherapy: A combination of several antiretroviral drugs which are given in a specific regimen in order to slow down or stop the activity of HIV in the human body.

Attachment Disorder: A mental and emotional condition which occurs during the first three years of life, and impairs a child's ability to attach, bond, or trust his/her primary caretaker.

Attachment Disruption: Any experience of disconnection between the child and primary caretaker that leaves the child feeling vulnerable and abandoned emotionally or physically, frequently or for a long period of time. Attachment disruptions include: drug and alcohol use by primary caretaker, unwanted pregnancy, death of caretaker, illness of caretaker, adoption, foster care, physical abuse, emotional abuse, sexual abuse, neglect of child's physical or emotional needs, maternal or caretaker depression or other mental illness or chronic illness.

Attachment Theory: A body of work examining the relationship between primary caretaker and child that impacts the psychological well being of the child and their ability to develop and function in relationships.

Autonomy: The sense of being in charge of one's self, and feeling independent.

CD4 T cell: Part of the immune system that is attacked by HIV. People who are infected with HIV often have too few CD4 T cells. CD4 T cells play an important role from the immune system that fights infection.

CDC: An acronym for the U.S. Centers for Disease Control.

Chronic Illness: An ongoing medical problem that cannot be cured but may be controlled, such as HIV.

Depression: A feeling state characterized by intense feelings of sadness, hopelessness, worthlessness and guilt. These feelings are often accompanied by fatigue, lethargy, and a diminished capacity to feel joy or take an active interest in activities or work.

Gastro-intestinal Tube: A tube surgically implanted into the wall of the intestine.

HARRT: A n acronym for Highly Active Antiretroviral Therapy, a combination of antiretroviral drugs.

Human Immunodeficiency Virus (HIV): A virus that attacks the immune system in the human body. It damages the immune system, which is the part of the body that defends and protects it from infection and other diseases. In order for HIV to survive and make more of itself, or replicate, it must live in special cells of the body. HIV is a type of virus known as a retrovirus.

Individuation: Personal achievements which mark an individual's characteristics.

Internal Working Models: The internalization of early relationships which account for personality development and pathology.

Immunosupressed: Someone who experiences immunosuppression.

Immune System: The system in the human body which fights germs and prevents infections.

Lipodystrophy: The re-distribution of fat to the middle of the body. The patient's face and limbs becomes drawn and exceptionally thin. A hump also forms on the patient's back.

Opportunistic Infections: Infections which cause diseases in immune compromised people.

PACTG: An acronym for the Pediatric AIDS Clinical Trials Group.

Perinatal Infection: Any infection—in this case HIV virus—that is transmitted to a human baby while the baby was in the mother's womb or during birth.

Resistance: The reduction of a drug's ability to work against a specific germ or virus. Resistance is thought to occur when a drug's target mutates and changes its structure so that the drug can no longer bind to it and work as well as it used to.

Viral load: The amount of virus in the body.

Viral Replication: This occurs when the virus makes copies of itself using genetic material in human cells.

Wasting: Rapid weight loss.

Assumptions

The following assumptions are included in this study because they have already been established by previous research.

- Antiretroviral therapy is extremely vulnerable to the development of resistance mutations.
- Depression is a barrier to antiretroviral adherence.
- There is a non-adherence trend in the HIV-infected adolescent population.
- Impediments to the developmental aspects of adolescents naturally propel these adolescents towards non-adherence.
- There is significant importance to the strength of a child's early attachment relationship.

CHAPTER III

METHODOLOGY

This was an observational investigation which described the quality of attachment, rate of depression and medication adherence of adolescents with perinatally acquired HIV-1 infection. A mixed method exploratory design was used. Both qualitative and quantitative data was collected (Tashakkori and Teddlie, 1998).

Sample Selection

The participants of this investigation were selected from an existing sample of 47 perinatally HIV-infected adolescents, ages 14-18 years, who received their medical care at a large urban pediatric hospital. The participants were selected at random, with replacement, until a sample size of 20 was reached. Adolescents were excluded from participation if they had significant cognitive impairment (full scale IQ < 70). Also, adolescents with whom the researcher had regular clinical contact were not used in this study to prevent any subject from feeling pressured to participate due to this relationship. Each subject was offered a $25 stipend for each of their three study visits in order to assist with transportation costs to and from the study visit. This stipend was provided by the Shaw Research Grant for Allied Professions.

Procedures

Eligible participants were contacted by the principal investigator during a regularly scheduled clinic visit. The study was fully described to these adolescents and

their parents/caregivers; informed consent was reviewed and signed if the adolescents and parents elected to participate. Regardless of whether or not families indicated they wished to participate, the established standard of psychosocial care and services was maintained.

Visit One: Semi-Structured Qualitative Interviews with Subject and Caregiver

Information regarding the death of the biological mother and father, separation from primary caretaker due to illness, number and length of foster placements, and Protective Services reports on abuse and neglect were collected. During their first study visit, the subjects participated in a semi-structured interview with the primary investigator and were asked to describe what they recall, know and feel about their early caregivers. The subjects' caregivers participated in a semi-structured interview with the primary investigator to provide information regarding the subject's early family history of separation, loss, and/or trauma as well.

Visit Two: The Beck's Depression Questionnaire and the Peer and Parent Attachment

Inventory was completed by the adolescent. The adolescents and parents/caregivers completed an adherence questionnaire to provide information regarding the child's adherence to medication during the prior three days.

Visit Three

The primary investigator provided each participant with the opportunity to debrief and review their experience of the study.

Instrumentation

Semi-Structured Iinterviews

All subjects participated in a semi-structured interview with the primary investigator. The subjects were asked to identify their early caregiver(s), what they remember and know about their caregiver, and how they feel about him/her. The current caregiver of the adolescent was interviewed by the primary investigator to provide information on their recollection and feelings about the subject's early caregiver, whether herself/himself or others.

Beck's Depression Inventory-Second Edition

This was a 21-item self-report instrument for measuring the severity of depression in adults and adolescents aged 13 and older. This version of the inventory was developed for the assessment of symptoms corresponding to criteria for depressive disorder as defined by the American Psychiatric Association's *DSM-IV*. The psychometric properties of this inventory include high reliability, regardless of clinical population, and adequate internal consistency and test-retest reliability (Beck et al., 1996).

Inventory of Peer and Parent Attachment (IPPA)

This was a self-report questionnaire with a five-point Likert-scale response format. Three broad dimensions of attachment were assessed: degree of mutual trust, extent of anger and alienation, and quality of communication. The revised version

(Mother, Father, Peer) was used and was comprised of 25 items in each of the mother, father and peer sections, yielding three attachment scores. Psychometric properties of the IPPA were adequate. Internal reliabilities for mother attachment, father attachment and peer attachment were .87, .89 and .92 respectively (Greenberg and Armsden, personal communication, 2005). In a sample of 10-16 year old psychiatric patients, less secure parent attachment was related to the diagnosis of depression, parent rating of the adolescents' depressive symptoms, and to patient self-report of depression (Armsden, et al., 1991).

Adherence Questionnaire (PACTG)

This questionnaire was completed by the participant and parent/caregiver during the interview with the primary investigator. The names of medications and the number of expected doses of medications were recorded. The adolescent and/or parent/caregiver reported the number of doses which were successfully taken during three prior days. Reasons for non-adherence were recorded as reported by the adolescent and as reported by the caregiver.

Data Management and Analysis

The information from this descriptive investigation was analyzed both quantitatively and qualitatively. The quantitative descriptive information was coded, scores from self-report measures were derived, and the percentage of full adherence was determined. All data was entered into a database and synthesized (Creswell, 2003).

The qualitative data was transcribed from audio tape into text. The text was read through in its entirety in order to derive a general sense of the overall meaning of the data at this stage. The data was coded by selecting segments of sentences and placing them into labeled categories. The coding process was used to generate a description of the categories or themes for analysis (Creswell 2003).

These themes were examined and a narrative passage was used to describe these findings. The data was interpreted by the researcher and meanings were made based on what the researcher learned from the data (Creswell, 2003).

CHAPTER IV

RESULTS

Description of the Sample, Quantitative Data, and Qualitative Data

The subjects of this investigation were selected from a pool of 47 adolescents, ages 14-18 years, who receive their medical care from a large pediatric hospital in an urban area. The subjects were selected randomly, with replacement, until the sample size of 20 was obtained. Adolescents were excluded from participation if they had a significant cognitive impairment (full scale IQ < 70), or if they were not on an anti-retroviral medication regimen.

The demographics of the population include: six African American females, five African American males, two Puerto Rican males, two Puerto Rican females, four Caucasian females, and one Caucasian male. Four 14 year-olds, five 15 years-olds, five 16 year-olds, four 17 year-olds, and two 18 year-olds participated.

Table 1: Demographics of Population

Ethnicity:	**African American**	**Puerto Rican**	**Caucasian**	**Total**
Female:	**6**	**2**	**4**	**12**
Male:	**5**	**2**	**1**	**8**

Table 2: Age of Subjects in Population

Age	14 year-old	15 year-old	16-year old	17-year old	18-year old
#Subjects:	**4**	**5**	**5**	**4**	**2**

History of Loss

Although each subject has a unique family history, the theme across all of the families was one of devastating loss. Fourteen, possibly 16, subjects were born to mothers who were intravenous drug users. Two of these mothers survived, recovered, and found their way back to their children, due to the supportive involvement of the maternal grandmothers. However, 12 birth mothers passed away, and two birth mothers were lost to the streets. The literature estimates that 52% of HIV infected children are born to mothers who are intravenous drug users, however, the percentage is higher for this population. Seventy percent of the subjects involved in this project were born to intravenous drug users. Subsequently, there was a high probability that the subjects were exposed to drugs in utero.

Sixteen of the subjects lost their birth fathers, or their birth fathers are missing. Fourteen of the subjects lost their birth mothers. Twelve lost both parents. Two subjects were cared for by both birth parents.

Table 3: Deceased Birth Parents and Lost Siblings

Deceased Father	Deceased Mother	Both Birth Parents Deceased	Lost Contact with Siblings
16	14	12	5

In addition to lost birth parents, there were five subjects who lost contact with their biological brothers and sisters. Because the families were fragmented by the fatality of their birth mothers' illness, abuse and neglect, and/or death, the subjects and their siblings were often separated and placed in different homes. Several siblings remained with their birth mothers because they were not HIV infected and did not require a higher level of care. Due to changes in placements throughout the years, many subjects lost track of their siblings.

Mode of Transmission

Although 19 of the subjects contracted HIV from their birth mothers, their birth mothers acquired the virus in several different ways in the late eighties and early nineties. Fourteen women were intravenous drug users who contracted HIV from unsanitary needles or from engaging in prostitution to support their drug habit. There were two birth mothers who are alive today, who were suspected of having used intravenous drugs, but who would not substantiate this suspicion for obvious reasons. There were three birth mothers who did not use intravenous drugs, but contracted HIV from their husbands who were either intravenous drug users or who had multiple partners outside of the marriage.

The subject who did not acquire the virus from his mother during birth had an HIV infected father who was an intravenous drug user. It was suspected that the subject contracted HIV from his birth father when he was between six and seven years old.

Table 4: Mode of Transmission

Acquired at Birth from IV Drug User	Acquired at Birth from Suspected IV Drug User	Birth Mother Who Acquired from IV Drug Using Partner	Acquired from Father Who Was IV Drug User
14	**2**	**3**	**1**

Placement Histories

Due to the loss of one or both parents, or neglect at the hands of a birth parent, the placement histories of the subjects also varied. Seven of the subjects went into foster/adoptive care within their first year of life. Three subjects were taken away from their birth mothers, due to maternal illness and death or abuse and neglect, and were placed in foster/adoptive care when they were three years old. Two subjects were abandoned by their birth mothers in middle childhood, and were placed in foster/adoptive care.

Table 5: Age of Attachment Disruption and Placement

Age Taken Out of Birth Mother's	Before One Year	Between 1 and 3 Years	Five, Six and Seven Years
# of Subjects	7	3	2
# Adopted	3	0	1
# w/Relative	1	1	1
# Foster Care	3	2	0

Out of the nine subjects who lost their mothers before the age of three, there were three subjects who were placed in relative foster care with maternal aunts and grandmothers. Upon entering the system initially, most subjects transitioned from foster home to foster home, but are now stable in their current foster/adoptive homes. There were two subjects who have not had stable placements. One subject's grandmother relinquished custody five years ago. The subject was placed in a residential facility for two years before the state placed her with an aunt. The second subject lost her foster/adoptive mother in a tragic accident. Currently, she is transitioning from relative to relative.

Current Living Situation

As a result of their placement histories, the subjects' current living situations differ. Eight of the subjects have birth parents who are alive and with whom they reside. Four of these subjects live with their birth mothers, however, two of the subjects,

initially, spent several years living with their maternal grandmothers. Two subjects live with their birth fathers, and two live with both birth parents. Five of the subjects live with foster parents, three live with relatives, and four of the subjects live with adoptive parents.

In sum, 40% of the population live with a birth parent; 35% live with their birth mother, and 10% live with their birth father. Forty percent live in foster/relative care and 20% live in adoptive care.

Table 6: Current Placements

Currently Live w/ Birth Mother	Currently Live w/ Birth Father	Live w/ Birth Parents	Maternal GM, but Now Birth Mother	Currently Adopted	Currently w/ Relatives	Currently w/ Foster Parent
2	2	2	2	4	3	5

Two of the subjects who currently live with their birth mothers had similar placement histories. Both of their birth mothers, shortly after they were born, left the subjects in the care of their maternal grandmothers. The mothers explained that they could not face the reality of their diagnosis and their baby's diagnosis, so they used drugs to escape. Eventually, these birth mothers rehabilitated themselves, found their way back to their families, and supportively resumed the role of primary caretaker for the subjects. There was one birth mother who left her baby with her mother and did not return from the streets. It was suspected that she may have been murdered.

There were two subjects who currently live with their biological fathers. These subjects lived with both birth parents until they reached middle childhood, and then lost

their birth mothers to the virus. Thankfully, their birth fathers are healthy and continue to care for them. Lastly, there were two subjects who did not lose either birth parent. Both birth parents still care for them.

Quantitative Findings: Adherence, Depression, and Attachment Adherence

The adherence questionnaire was written by the primary investigator and requested information on the subject's missed doses, and average of missed dosages between each clinic visit since the age of 14.

Seven of the subjects were found to be adherent to their anti-retroviral medications, and 13 were non-adherent. This finding was consistent with the literature, which indicates that due to the challenging nature of antiretroviral medication regimens and the oppositional tendencies of adolescents, many adolescents are at risk for immunological failure (Van Dyke et al., 2000; Murphy et al., 2001; Dolezal et al., 2003; Mellins et al., 2003; Steele & Grauer, 2003). High rates of non-adherence are observed among adolescents with HIV infection (Hosek et al., 2002; Murphy et al., 2001; Murphy et al., 2003).

Depression

The subjects' level of depression was measured with the Beck's Depression Inventory-Second Edition. This was a 21-item self-report instrument for measuring the severity of depression in adults and adolescents aged 13 and older. This version of the inventory was developed for the assessment of symptoms corresponding to criteria for diagnosing depressive disorder listed in the American Psychiatric Association's *DSM-IV*.

The psychometric properties of this inventory included high reliability with internal consistency and test-retest reliability (Beck et al., 1996).

One of the subjects scored in the clinical range on the Beck's Depression scale. Nineteen of the subjects' scored below the clinically depressed range. This finding contradicted the literature on the subject of high rates of depression in HIV infected adolescents; many adolescents with HIV infection are at significant risk for depression, a known contributor to poor adherence (Hosek et al., 2002; Rabkin & Chesney, 1999; Starace et al., 2002).

The distress associated with a chronic illness compounded by the specific circumstances relating to HIV/AIDS, such as maternal depression, the stigma of HIV/AIDS, and the fatality of the illness, increases an adolescent's risk for depression threefold (Greenberg, Cicchetti & Cummings, 1990). Maternal death before the age of 11, the absence of an adequate caregiver after the loss of the mother, and family conflict also contribute to the risk for depression (Parkes et al., 1991; Armsden & Greenberg, 1987; Greenberg et al., 1990).

Due to the contradiction between the findings of this study and the literature, the qualitative data regarding depression was analyzed. It became clear that the Beck's Depression Scale was not an infallible gauge of depression for this population. During the qualitative interviews, all 20 of the subjects acknowledged negative feelings about being different.

Above all, the subjects longed not to be viewed as different or deficient. In addition, four subjects confessed during their interviews that they were, in fact, depressed. Several responses on the Beck's Depression Scale were phrased concretely,

clearly, and were easily distinguished as normal or abnormal feelings and behaviors. This researcher believes that the subjects' most pronounced and universal desire, to be viewed as normal, influenced some of their responses.

Statistical Significance

Although the subjects did not score as clinically depressed on the Beck's Depression scale, a statistically significant difference was found in the depression scores between the adherent and non-adherent subjects. The adherent subjects were less depressed. In spite of the subjects' attempts to disguise their depression, a significant relationship was discovered * $t = -2.103$, $p = .05$. This finding was consistent with the literature, which recognizes depression is a recognized contributor to poor adherence (Hosek et al., 2002; Rabkin & Chesney, 1999; Starace et al., 2002).

Attachment

According to Gay C. Armsden and Mark T. Greenberg, authors of the Inventory of Parent and Peer Attachment Scale, because adolescents are separating and individuating from their parents, attachment style in adolescence should be scored in three domains, attachment to maternal caregiver, paternal caregiver, and peers. The attachment scores were categorized as secure, insecure, and avoidant (Greenberg and Armsden, personal communication, 2005, 2006, 2007).

This was a self-report questionnaire with a five-point Likert-scale response format. Three extensive dimensions of attachment were assessed: degree of mutual trust, extent of anger and alienation, and quality of communication. The revised version was

utilized and included 25 items in each of the mother, father and peer sections. The psychometric properties of the IPPA were sufficient. The internal reliabilities for mother attachment, father attachment and peer attachment were .87, .89 and .92 respectively (Greenberg and Armsden, personal communication, 2005, 2006, 2007).

Attachment and Adherence

Five of the seven adherent subjects scored as securely attached to their maternal caregiver. Also, five scored as securely attached to their paternal caregiver. Four of the seven adherent subjects scored as securely attached to their peers, and three scored as securely attached in all three domains: maternal caregiver, paternal caregiver and peers. The important finding in this area was that six out of the seven subjects who were adherent also scored as securely attached to at least one caregiver.

Table 7: Attachment Styles

Adherent Subjects	**E (Adopted)**	**V (Birth M)**	**H (Adopted)**	**T (Birth M)**	**M (Birth M)**	**N (Adopted)**	**F (Birth Father)**
Attachment to Maternal	**Avoidant**	**Secure**	**Secure**	**Secure**	**Avoidant**	**Secure**	**Secure**
Attachment to Paternal	**Avoidant**	**Secure**	**Secure**	**Secure**	**Secure**	**Insecure**	**Secure**
Attachment to Peers	**Secure**	**Secure**	**Secure**	**Secure**	**Insecure**	**Insecure**	**Insecure**
Depression	**Not Depressed**	**Not Depressed**	**Not Depressed**	**Not Depressed**	**Not Depressed**	**Not Depressed**	**Not Depressed**

The subject who was adherent, E, did not score as securely attached to one or both caregivers, but did score as securely attached to his peers. E suffered a great deal of medical neglect during his first three years and may have an attachment disorder. However, he is at an age where he can meet some of his attachment needs through his peers. The more logical explanation for E's adherence was his medical situation. He currently takes 15 different medications due to his HIV, and has had a recent organ transplant. According to E and his caregiver, if he does not take his medicines, the consequence is an immediate trip the Emergency Room. E feels this provides him with quite a bit of motivation to take his medicines.

Out of the seven adherent subjects, three subjects, T, H, and V scored as securely attached in all three attachment domains. F scored as securely attached to both caregivers, but scored as insecurely attached to peers. M and N scored as securely attached to one caregiver. E scored as avoidantly attached to both caregivers, but securely attached to his peers.

The crucial finding in relation to adherence and attachment was that all of the adherent subjects were securely attached in at least one domain. Six out of the seven adherent subjects had a secure attachment to at least one caregiver and four of these subjects had secure attachments to both caregivers.

Non-Adherence and Attachment

Of the 13 non-adherent subjects, five scored as securely attached, four scored as insecurely attached, and four scored as avoidantly attached. Because an equal number of non-adherent and adherent subjects scored as securely attached to their caregivers, the

relationship between attachment and adherence was further analyzed using the qualitative data. This analysis will be presented with the qualitative findings.

Yet, there was one domain in which the quantitative scores spoke for themselves. In the peer domain, 11 out of the 13 non-adherent subjects scored as securely attached to their peers, which was a compelling finding when integrated with the qualitative data.

For instance, all of the subjects stated in their interviews that they "felt different" because of the medicines. The majority of the subjects kept their virus a secret from their friends, due to the stigma of the illness. The subjects who decided to disclose their illness to their friends had negative experiences.

Many subjects indicated that taking medicines several times a day interfered with their ability to spend time with their friends and participate in the types of activities in which their friends were participating. This situation was also exacerbated because many subjects felt nauseated for several hours after taking the medicines. Therefore, the medicines not only interrupted and prevented the subjects from spending time with their friends, but also they were a barrier to emotional closeness because the medicines represented an aspect about the subjects which could not be shared (Archer and Burnell 2003). This conflict was repeated in their romantic relationships as well.

Attachment and Maternal Caregiver

Overall, in regards to their attachment to maternal caregivers, 11 subjects scored as securely attached to their mothers. Five subjects scored as insecurely attached, and four scored as avoidantly attached to their maternal caregiver. The quantitative scores

were compared to the subject's qualitative data to check for consistencies or inconsistencies in order to evaluate the authenticity of the responses.

Table 8: Maternal Attachment Scores for Population

M=Maternal Caregiver

Secure Attachment to M	Insecure Attachment to M	Avoidant Attachment to M
11	**5**	**4**

Because several subjects had multiple maternal caregivers, they scored the survey according to the maternal caregiver they feel had the most impact on their lives during their early years. Of the 11 subjects who scored as securely attached to their maternal caregiver, two scored the survey in relation to their deceased birth mothers, seven scored the survey in regards to their adoptive/foster parents and two scored the survey in relation to their birth mother who is caring for them today.

Table 9: Securely Attached to Maternal Caregiver

S/A=Securely Attached

M=Maternal Caregiver

S/A to Deceased Birth M	S/A to Adoptive /Foster M (adopted before one)	S/A to Adoptive /Foster M (adopted at 5)	S/A to Birth M
2	**6**	**1**	**2**

For example, the two subjects, A and F, who lived with their birth fathers, answered the survey in relation to their feelings about their deceased birth mothers. A's

birth mother passed away when she was six. When her quantitative score (secure maternal attachment) was compared to the qualitative data, however, it was assumed that she may have an idealized representation of her deceased birth mother.

She stated in her interview, "My mama was cool, calm, relaxed, and when she said something, she meant it. When somebody got out of line, she would let them know nicely. She was loving and caring." However, the reports from the medical team and her husband indicate that A's mother was verbally aggressive, dramatic, oppositional, and head strong. This subject's idealization was reflected in her lofty quantitative score for maternal attachment.

The second subject, F, who answered the survey in relation to her deceased birth mother, lost her mother when she was five. The subject's score regarding maternal attachment corresponded with the data in her qualitative interview. Despite losing her mother at an early age, F was able to recount several positive and detailed memories of her birth mother during the interview. One memory included drawing pictures for her birth mother when she was ill and in the hospital. F states,

> I would visit her and bring her my pictures. She would hang them on the wall until her hospital walls were covered with my drawings. She hugged me all of the time. Everyone said we were so attached. I wish we would have had more time together.

F's secure attachment score to her deceased birth mother seems accurate.

Six securely attached subjects, who were placed within their first year, answered the survey in relation to their adoptive/foster mothers. The subjects spoke positively about their mothers in their qualitative interviews. More importantly, these subjects acknowledged conflicts in their relationships with their mothers. Their ability to identify and verbalize conflicts and differences, yet, maintain feelings of connection and

closeness despite these differences validates the security of these relationships (Bradley, 2000).

For example, referring to her adoptive mother subject H stated,

> My mom listens to me and accepts who I am. She is really fun to be with, and she has always taken really good care of me. The only time we fight is when I try and wear something that she calls, "scandalous." She is partly joking, but she makes me change anyways. She has issues with me growing up too fast.

This statement represents the healthy conflicts that exist within a normal teenage daughter and mother relationship.

One subject, L, who scored as securely attached to her maternal caregiver scored her survey in relation to her adoptive mother who adopted L at age six. Tragically, this adoptive mother passed away in an accident when L was 13. L had a difficult time expressing her feelings about her adoptive mother in the qualitative interview; however, it appeared she felt less vulnerable answering the survey questions. The medical team indicated that she had a very close relationship with her adoptive mother when she was alive.

Two of the subjects who scored as securely attached to their birth mothers, T and V, are with their birth mothers today. The qualitative interviews of these subjects validated their quantitative scores. The caregiver interviews contained multiple positive attributions made towards the subjects as babies, and the subject and caregiver interviews included explicit and positive shared memories of their subjects as they were growing up.

A critical finding regarding the relationship between this population and maternal attachment was that six out of the seven securely attached subjects were either adopted/fostered within their first year, or they were cared for by their birth mothers or

birth fathers from birth. These subjects remain with their adoptive/foster parents or birth parent today.

None of the subjects who were adopted or fostered after the age of one year have a secure attachment to their caregiver. This finding will be discussed further in the qualitative data discussion.

Insecure Attachment to Maternal Caregiver

Five subjects scored as insecurely attached to their maternal caregivers. Two of these subjects, X and Y, currently live with their birth parents and have always lived with their birth parents. When their quantitative scores were compared to the qualitative data, the accurateness of the subjects' insecure attachment style was confirmed.

For example, neither subject could recall any positive or specific memories of their birth mothers growing up. Similarly, the birth mothers were the two out of the three caregivers in the study who did not comment positively about the subject as a baby. In addition, the birth mothers qualified themselves as "good mothers" because they provided for the child's biological needs. They fed and clothed their child. One proudly stated, "She never went to be without any supper." Yet, they did not comment on any emotional aspect of their relationship with their child.

Another subject, Q, who scored as insecurely attached to his maternal caregiver currently lives with his birth mother. Q lived with his maternal grandmother for his first few years of life. Reportedly, his maternal grandmother was a very loving and responsible caregiver, and supported her daughter in her recovery from drug addiction. The subject's mother, with the support of her own mother, returned as Q's primary

caregiver when Q was five. The insecure attachment score seemed understandable, due to birth mother's early separation and sporadic visits during her recovery. However, Q's score was very close to the securely attached range, so Q and his mother seem to have a promising mother-son relationship.

Two subjects, P and Z, who scored as insecurely attached to their maternal caregivers, scored the survey in relation to their foster/adoptive mothers. Both P and Z were placed in the care of relatives and friends when they were toddlers. These early caregivers became their long-term caregivers. The qualitative data supported the scores of P and Zs quantitative scores. Although they had long-term caregivers, the age at which they were separated from their birth mothers is pivotal. There is an important finding about separation in toddler-hood that will be explored in the qualitative data section, in addition to the continued examination of the qualitative interviews of P and Z.

Table 10: Insecure Attachment to Maternal Caregiver

IA= Insecure Attachment

M=Maternal Caregiver

I/A to Birth Mother (Lives with both birth parents)	**I/A to Adop/F Mother**	**I/A to Birth to Mother: (Returned as Caregiver when subject was 5)**
2	**2**	**1**

Avoidant Attachment to Maternal Caregiver

After cross checking the qualitative data with the quantitative scores, an important finding regarding the four subjects who scored as avoidantly attached to their maternal

caregivers was established. The four subjects who were avoidantly attached to their caregivers were also the subjects who endured the most extreme cases of abuse and neglect. Although these subjects' stories were referenced, they will be thoroughly examined in the qualitative section of this paper.

For instance, one of these subjects, E, had one of the most documented cases of extreme medical neglect for the first three years of his life. Thus, it may be impossible for him to attach to another caregiver, as he seemed to suffer from an attachment disorder.

Another subject, M, was thought to have suffered sexual abuse at an early age, perpetrated by his birth father, who is now deceased. Also, he frequently witnessed his father abusing his mother when he was very young. It was clear from his and his birth mother's interview that he blamed his mother, thus, their relationship has been adversely impacted by his early experience of trauma due to abuse and domestic violence.

Another subject, C, was placed with her great aunt who had many children of her own. They lived in the projects and C reported that she was sexually abused while she lived with her great aunt. This was reflected in her avoidant attachment style, as well.

The last subject, K, lived with her birth mother until she was seven. She also gave detailed accounts of her experience of abuse and neglect before she was adopted at the age of seven. She remembered living in and out of cars, watching her mother shoot up and prostitute herself, and, most clearly, she stated she remembered being hungry all of the time. She says she horded food so she could feed herself and her brother because her mother would not come home for days on end.

The last important finding regarding maternal attachment was the relationship between maternal attachment and peer attachment. Although it was not as statistically

significant as the relationship between paternal attachment and peer attachment, there was a correlation. Expanding and intensifying peer relationships is one of the primary tasks of adolescence, and the quality of the maternal attachment relationship impacts the subject's capacity for achieving age appropriate developmental tasks. As a result, it seemed logical that a healthy maternal attachment led to healthy peer attachments.

Paternal Attachment Scores

In relation to the subjects' attachment to their fathers, nine subjects scored as securely attached, seven scored as insecurely attached, and four scored as avoidantly attached.

Four of the subjects scored this survey in relation to how they felt about fathers who are deceased or missing. Three subjects scored the survey in relation to how they felt about their adoptive fathers. Two subjects scored the survey in relation to their birth fathers who are alive. One critical finding regarding the fathers in this study was that ten out of the 20 subjects have never met their birth father.

Table 11: Paternal Attachment Score

Secure Attachment	Insecure Attachment	Avoidant Attachment
9	7	4

F=father

Scored in Relation to F	Secure Attachment	Insecure Attachment	Avoidant Attachment
Deceased Birth F	4	0	2
Adoptive/Foster F	3	4	2
Birth Fathers	2	3	0

The qualitative data indicated that some of the subjects idealized their birth fathers who have passed away. For example, one subject stated, "He was a big time baller. He had a car with rims." One birth mother echoed this phenomenon,

> He never held on to anything I gave him, but he sure held on to what his dad gave him…..like that piece of crap mini- bike. He still has everything. He would rather die then let me get rid of that junk. …And he's seen his dad twice in his life.

Yet another subject stated, "He gave my mom AIDS, but I still think he was a good guy." These subjects presented idealized representations of their fathers, whom they have only seen once or twice in their lives.

Conversely, there are subjects who expressed anger towards their birth fathers who have died or who are missing, and therefore, not involved in their lives. One subject stated, "I met my dad one time, and I never heard from him again." Another subject said,

"I never met my dad. He sent me a letter one time and spelled my name wrong." "He was a crack head, that's what I heard 'cause I never met him," stated another subject.

Yet another subject acknowledged that it was common knowledge on the street that her father murdered her mother. Many other subjects seemed ambivalent about their fathers. They stated ambivalently in their interview that they have never met their fathers or even know if they are alive.

Whether these subjects had an idealized, ambivalent, or angry relationship with their birth fathers, it was imbued with intense feelings that had to be defended against. This defensive psychological structure had an enduring impact on their attachment style. For example one subject, E, scored as avoidantly attached to his adoptive father, however, his qualitative data conveyed the engaging, and empathic nature of this father.

In regards to his adoptive father, the subject lit up and stated, smiling and laughing, "My dad is weird and crazy. Sometimes he makes funny jokes and tries to act cool and that makes me laugh. He's always goofing around. He wants to be cool like me."

This was the only time throughout the interview that the subject showed any affect. In addition, the subject's adoptive mother said it was her husband who gets E to take his medicines when he gets tired of taking them. She said she does not know how her husband does it, but he gets E smiling and laughing and stays with E for sometimes hours until E takes his medicines. This was an example of a quantitative score which reflected the subject's resistance and unconscious fears about attaching to another father, although he was presented with a loving one.

Attachment to Peers

In relation to the subjects' attachment to peers, 11 subjects reported a secure attachment to their peers. Eight subjects reported an insecure relationship to their peers and one subject reported an avoidant attachment relationship to their peers.

Table 12: Attachment to Peers

Secure	Insecure	Avoidant
11	**8**	**1**

Statistical Significance

The important finding in this area was the correlation between the subject's attachment to their fathers and their attachment to their peers. The more securely attached the subjects were to their paternal caregivers, the more securely attached they were to their peers. This correlation was found to be statistically significant * $r = .566$, $p < .01$, and was consistent with what the literature states about child development and the two main phases of separation and individuation, toddler-hood and adolescence. As the relationship with the primary caregiver becomes more diffuse, the child is able to foster deeper attachments to others, for example, a father in toddler-hood and friends in adolescence.

Summary of Quantitative Findings

In all, there were several important findings derived from the quantitative data. Two of these findings were found to be statistically significant. The first finding was the relationship between paternal attachment and peer attachment. The higher the attachment

score for the paternal caregiver, the higher the attachment score to peers. The second finding was the relationship between depression and adherence. The adherent subjects were less depressed.

There were additional significant findings which pertained to attachment. Six out of the seven securely attached subjects were adopted by long-term caregivers before the age of one. The two subjects who were adopted as toddlers had insecure attachment and avoidant attachment styles to either adoptive parent. The avoidantly attached subjects were the most traumatically abused and neglected, and have contradictory attachment data between the qualitative and quantitative data, which was explained by their defensive structures. Lastly, there was a finding about fathers. There were ten subjects who had not met their birth fathers.

Qualitative Data

Nine themes were present across the entirety of the qualitative data and were developed into categories: Lost birth mothers (separation in the first ten months, toddler-hood, and middle-childhood), Lost siblings, Displacement, Death sentence, Found birth mothers, “How did this happen to me and my child?”, Shared memories, Alive with no memory, and Early attributions. These categories included data which elaborated on the experiences impacting the subjects’ level of depression, quality of attachment and developmental maturity.

Lost Birth Mothers: Separation in the First 10 Months

The major finding from the qualitative data was the "lost birth mothers" category. Twelve birth mothers passed away or were lost to the streets for years. The seven subjects who lost their birth mothers within the first 10 months of life reported yearning to know what their birth mothers were like. Not all of these subjects had memories of their birth mothers, but all had longings. One subject stated in her interview, "I don't remember anything about her, but everybody tells me I have her smile, and I know I do. She had a great smile. That is what everybody says."

Another subject stated, "I don't remember her, but I know she was really nice and easy to talk to. She was kind." Still another subject stated, "I wish I could see her now. I think I might look like her. I wonder if I have her eyes." In contrast, another subject reported, "I wouldn't be in this situation right now, if it weren't for her. I wish she was here so I could tell her how I feel. I wish she was here, so we would, at least, have each other." Some subjects were angry and some were not, but all of these subjects wondered and wished for their birth mothers.

Two of these subjects experienced early medical trauma and attachment disruptions. One subject, N, was born several months premature to an intravenous drug user. She spent the first few months of her life in the hospital and she was not an easy baby to soothe. The nurses dreaded a shift in which they had to watch her, so she would get handed off quite a bit. Eventually, a new resident came to the hospital and she believed that if N had one consistent caretaker at the hospital, N would improve. So, N was assigned to her, and she made enough progress for her adoptive family to take her

home. Her adoptive father stated, “They never thought she would survive, but she sure did!”

When she was asked about her birth mother, N said,

> I haven’t seen her for a couple of years. She might be dead, I don’t know. I know she was doing bad things like doing drugs, and drinking and she had a different boyfriend every night. I don’t think he (adoptive father) thinks she is a good person.

N was adherent to her medications.

The second subject, R, who experienced early medical trauma because she was born prematurely to an intravenous drug user, had a similar prognosis. The medical professionals did not predict that she would live, however, she survived. Two weeks after she was born, her mother passed away in the same hospital. After spending three months in an inner-city, non-pediatric hospital which did not have a good reputation in the community, R was adopted. She stated she did not know when her mother died, and seemed annoyed at the question. She stated “I don’t know. Maybe it was in the hospital where I was born.” The undertones of this statement seemed ambivalent. R was not able to expand on her feelings about her birth mother, which compelled this interviewer to believe the subject had some repressed rage.

R was born addicted to heroin and was probably very difficult to soothe because of her addiction. She spent her first three months of life at a hospital that was not staffed or equipped to cope with a child in such a condition. In addition, R suffers from some gastro-intestinal problems related to her drug exposure in utero, and presented as depressed. R was non-adherent which adds support to the hypothesis that she may have repressed hate and anger which she turned on herself, as evidenced by her behavior.

In addition to early medical trauma and early separations from their birth mothers, one subject, H, experienced multiple early attachment disruptions. Her adoptive mother described the story:

> Her birth mom went to an adoption agency three weeks before she was due, and a couple agreed to adopt her when she was born. They had a hotel room right across the street from the hospital. For some reason, the hospital staff decided to test H, and they discovered her to be HIV positive.
>
> The couple talked about it, but decided to change their minds. The director of the adoption agency picked H up from the hospital and tried to place her. He could not find a home for her, and all of the group homes were filled, so he brought H to his own home. He didn't want to turn her over to the state because he'd heard such horror stories. Then, about two weeks later he brought her into the Emergency Room. I was working when I heard the triage nurse say, 'They are bringing baby H in….beautiful baby, terrible situation.' So, I asked what the baby's story was, and it was a very sad story. Well, she ended up as my patient that night and there was something about her. She had a presence. She was sweet and peaceful, like somehow she was an old soul in a baby's body.
>
> The social worker took her that night. I went home after work and talked to my family about fostering her. It took us a few days to come to the decision, and we had to go through expedited foster parent classes, but within a few months, she was home with us, and in a few months we adopted her. The rest is history.

When H was asked about her birth parents she said,

> I've always wanted to meet them. We don't think my mom is alive, but we think my birth dad is. I don't miss them because I never knew them, but I am curious. Like, what does she look like? In school they talk about heritage, and I don't know if I am Italian or Lebanese. It's kind of funny, actually, because I don't have to write those dumb papers.

H was adherent to her medications.

Although this subject found herself in a loving home within four months, there were some that did not. One subject, B, who lost his mother shortly after birth, was placed in a neglectful foster home until he was a year old. His adoptive mother stated that when she met him for the first time B had such a severe case of diaper rash that there was

blood on his diaper. She also described his crib as a "cage" with bars going across the top. She said she suspected that the foster mother did not hold or rock B. She stated,

> When I got B he didn't cry, he didn't smile, he didn't do anything. He just lay there. You know, when a baby cries, the mother goes to the baby, when the momma never comes, the baby never cries no more.

When asked about his birth mother B became angry, "She was a junky. She got the easy way out. I wish I were dead. Then, I would be with her." B was non-adherent.

Another subject, C, who lost her birth mother soon after she was born was placed in her great aunt's care. She grew up in one of the roughest areas in the city. She lived with her great aunt, her great aunt's kids, and many cousins in a one bedroom apartment. When she was ten, she remembered being sexually abused by a family member. C has been in an out of residential placements and relative placements since she was 12, and was non-adherent.

When she was asked about her birth mother in the interview she stated, "I don't know what happened to her. They say she was murdered by the person who was supposed to be my daddy." Like all of the subjects who lost their birth mothers in infancy, she never knew who her birth father was either. "I think my mom had a good personality. Everybody says I'm just like her; outgoing and stuff. I wish she was here," C said of her birth mother.

Still another subject, J, was taken away from her mother when she was four months old because she and her mother were living on the streets and her mother was doing drugs. J was placed in a group home, and the state asked her aunt to take over guardianship. Luckily, her aunt agreed.

J's aunt described the story.

> It was the end of the day and I had an awful cold. I had just gotten off work when I got the call about J, and I turned them down. I just thought, I am barely taking care of myself right now, so what am I going to do with a baby?" I got on a bus to go home, and I just kept thinking about her. So I got off and got back on going the other way. I picked her up and she was in this puffy little pink snow suit and I could barely see her peeking out. So, I put her on my lap on the bus and we went home. And, she was so quiet. I thought, what is wrong with this child? But, I got her home, and put her down and she laid there like a little snow man, all stuffed in her snow suit so she couldn't move. Well, I took her out of that snow suit and before I knew it she was smiling; those beautiful big eyes staring at me, and she grabbed my leg and wouldn't let go. I think she was saying to herself, "I better hold on to this mommy." Oh, she was so cute. I'll never forget those days. What a good baby.

J stated, when asked to speak of her feelings about her birth mother, "I kind of don't have any feelings for her. I never knew her because when she would come to visit me she was always high, so she would always pass out, or she would scream and yell at my aunt. I didn't like it. How you going to yell at the person who is taking care of your own child? I didn't even want to cry at her funeral. My aunt was crying, so she made me cry watching her, but my tears were not for her (birth mother). This subject was non-adherent.

The last subject, I, lived with his birth father for five months before his uncle before his uncle's girlfriend took over his care, and eventually adopted I. She remembered I being very clingy. She stated,

> I remember the first time I met I. He wanted me to be his mommy.… I could just tell. He knew I was the best. He was fascinated by my face….trying to rub my face and touch my face. He was a great baby.

This mother although seemingly loving, was reported to unnecessarily and frequently shame the subject at medical appointments in front of medical staff. Also, there was a narcissistic quality about her descriptions. I was non-adherent.

Six of these subjects did not know their birth fathers. Three of these subjects reported that they did not know if their birth mothers were alive or dead. Some of the subjects' who lost their birth mothers in infancy were fortunate enough to be taken in by loving caregivers, and they had a chance to bond with these caregivers in infancy and throughout their childhoods.

The circumstances surrounding an infant's attachment relationship and its disruption are imperative to understanding the development of psychopathology (Bradley, 2000). For some infants, an attachment disruption is a primal wound which creates a challenge for the new caregivers to form a bond (Archer & Burnell, 2003). Yet, a responsive and empathic caregiver can buffer the infant from the trauma of the disruption and deter the development of psychopathology (Bradley, 2000). Three of the subjects who experienced an attachment disruption in infancy seemed to have caregivers who had healthy self esteems and who were able to de-center in order to tolerate the child's difficulties in the attachment relationship long enough to form a bond with their child. Two of the three of these subjects were adherent.

Separated in Toddler-Hood

Toddler-hood is also a time when attachment disruptions are traumatic. Three subjects lost their birth mothers when they were toddlers. Two of these subjects were removed from their birth mother's care due to abuse and neglect. One birth mother passed away. Interestingly, the subjects who lost their birth parents in toddler-hood were the most idealizing of their birth mothers, the most depressed, and the least emotionally attached to their caregivers.

For example, one subject, E, endured and survived one of the worst cases of medical neglect the city has ever seen, per DCFS. Even so, E longed for his birth mother intensely. His adoptive mother described a story which depicts this phenomenon early on. She reported that E's birth mother came over unexpectedly for a visit. The adoptive mother decided she looked intoxicated, so she encouraged E's birth mother to go upstairs and lie down in the subject's bed until she felt better. So, E's birth mother went upstairs to lie down. E was playing with blocks in the family room and looked content, so the adoptive mother went into the laundry room to finish her laundry.

After a few minutes, she decided to check on E, but he was not in the family room playing where she had left him. She searched the first level of the house and yard, but she could not find him. She frantically ran upstairs to his bedroom and there she found him, peacefully curled up in a little ball against his birth mother's chest and she had curled up around him. There they slept for about two hours. Yet, when they awoke and she said, "Good bye," E appeared unaffected. He resumed his play with the blocks and didn't show any signs of dismay.

When asked about his birth mother during the interview, he stated, "She is smart and loving and fun." He described stories in which she had spent time with him, taking him on vacations, walking on the beach, playing basketball, and playing video games. The reality was his birth mother rarely came to visit him sober and she hadn't visited him in years.

The following story was told by E's adoptive mother and a nurse, in collaboration. They explained,

> When E was eight, E had a perforated organ, so he endured five surgeries. He never cried towards the end. He never smiled. He didn't talk. He wouldn't interact

> with anybody. Every nurse and doctor, there were six services involved in his care at the hospital, would take turns in his room trying to cheer him up, but he wouldn't even make eye contact with anybody, not even me. Finally, when they were trying to insert an IV and they couldn't get it right, he cried out, 'I want to go home!' All of the doctors involved in his care met and decided they had tortured E enough. They were going to let him go home to die peacefully because they knew he had given up. He was completely shut down.
>
> Then, his birth mom came to visit him for the first time in years. Three residents walked by his room and heard laughter and chatter. Stunned, they looked into E's hospital room and saw his birth mom sitting with him, and E had come back to life. He was smiling, chatting and joking. They were having a great time. She left later that afternoon, and E had the sixth surgery and recovered. He went home with me the next week, and he was okay
>
> .

This idealized fantasy about his mother, seemed to ward off any rage he had towards her. Yet, as a result of this idealization, the subject had not been able to connect with his adoptive parents, despite their continuous, loving attempts. His adoptive mother stated, "He will never love us like he loves her, but I understand, kids are really loyal to their parents. I just wish he would let us love him." This subject has never met his birth father and does not know who he is.

The second subject, Z, lost his birth mother when he was three years old and was adopted by his aunt and uncle. Similar, to E who lost his mother in toddler-hood, Z also had an idealized fantasy of his birth mother. He stated,

> My life would be totally different if she was still alive. I would be happy. I am sad all of the time because I think about her all the time. Everyday I think about how different my life would be if she was still here, and how great it would be. Without her I am sad. I think I am depressed.

During his interview Z disclosed feelings of hopelessness, extreme sadness, and some passive suicidal ideation, stating (in regards to the medicines), "I am just not motivated to stay alive." Z doesn't remember his birth father because he passed away when Z was an infant.

The third subject, P, lost her birth mother in early toddler-hood, when she was around two years old, and has a similar idealization. Her adoptive mother reports that the subject's birth mother lived on and off the streets, and was a heroin addict. P's adoptive mother stated,

> She would leave the kids with anybody. P's older brother said she would let people fondle them for heroin. He also said she used to shoot up in front of them. I was involved on and off. I would take the kids when she went into the hospital a few times, but she always took them back.
>
> Finally, the kids, P, and her older brothers, called me from the projects one day when I was at work. They remembered my work number, and they pleaded with me to come and get them. They were so scared. So, I left work to get them and there they were all alone in the projects. Anything could have happened to them. I took them home. Her mother never came in contact with them again. She died when P was six or seven.

When P was asked about her feelings about her birth mother, she stated,

> She was real laid back and sweet. We always we used to rub our noses together when we were excited. We called it "nu nu." When I was around her, there was no sadness. We were always happy when we were around each other.

She went on to describe how she felt at her birth mothers funeral when she was six or seven, "I was mad and sad. I thought I couldn't go on with life because she wasn't there."

P also stated in the interview that she has never met her birth father, but she knows he passed away a couple of years ago. She also said that he had left her a small amount of insurance money. P was non-adherent and disclosed feelings of depression at the end of the interview.

One of the most noteworthy findings about the subjects who lost their birth parents in toddler-hood, was that they were the most idealizing of their birth mothers, the most depressed, and the least attached to their caregivers. This suggested that a maternal

loss in toddler-hood generates a severe attachment disorder and future depression, and depression is a deterrent to adherence.

Separated in Middle-Childhood

There were two subjects who lost their birth mothers in middle childhood. Their stories were similarly distressing. One subject, K, lived with her birth mother and younger brother until she was seven years old. K's birth mother left K and her brother at a mental health agency in the city. Shortly after, K was adopted by a professional couple, but her brother was placed in a home for the mentally handicapped.

K described her feelings about her birth mother in the interview,

> You know, I can't remember anything about her. I can't remember what she looked like or her face. I think I suppressed her. I remember living in an apartment, then with friends or her boyfriends, then, we lived out of a car for a long time. She would forget to feed us and send us to school. It didn't seem like she made much of an effort to keep us ok. I do remember her shooting up in front of us with a spoon and a lighter. She didn't even care enough to be more secretive about it in front of her children.
>
> I got really sick one time, and my arm swelled up, but she never took me to the hospital. By the time she took me, I was in septic shock. I remember being really ashamed of her that time. I never saw her after I was adopted. When the adoption agency called to say that she died, I cried, but it wasn't because I was sad, it was because I knew I would never have a chance to confront her about everything she had done to us.

In the interview, K's adoptive mother described finding food hidden in the subject's drawers and in her closet when she first moved in with them. She thinks K had to hide food in case her mother did not come home or came home high and could not feed them, so she could feed herself and her brother.

The adoptive mother also explained that they would hear the subject crying in the middle of the night, but she would pretend to be asleep when they would check on her.

The family had two dogs that the adoptive mother would send into K's room when they heard her crying at night. K's adoptive mother said that as soon as the dogs snuggled in with K on her bed, she wouldn't hear K crying anymore. Ironically, at the end of her interview, K indicated that it was the family dogs that helped her adjust to her new home. She still has the dogs, and she seeks them out whenever she is upset about something or is sick. One dog is too old to jump up onto K's bed, so K makes steps for her out of boxes.

K was one of the least adherent subjects, and had low attachment scores. She had not met her birth father. She said her birth father sent her a picture of himself and his new wife, but she said he spelled her name incorrectly on the envelope. She hasn't heard from him since.

Like K, another subject, L, lost her birth mother at seven years old as well. She had a difficult time recalling the characteristics of her birth mother, also. She remembered living in and out of hotel rooms. L stated, "She was barely around because she was always high, but the times she was around it was good. She always wanted me with her. She always babied me. She never made me go to school."

When L was asked about what her mother looked like, she said, I don't really remember what her face looked like. I think she had blonde hair. I remember her tattoos and that she didn't have many teeth."

L's birth mother left her in the care of extended relatives who adopted L at age seven. L's adoptive mother passed away in a terrible car accident when the subject was 13 years old. L didn't want to comment on her adoptive mother, T, but she showed me

the charm necklace she wears around her neck everyday that has her adoptive mother's, picture in it. She stated, "I loved T. She was the best at helping me feel better."

L hasn't seen her birth father since she was four and stated she doesn't care to know him. Currently, L is living out of a hotel room with a relative, has dropped out of school, and is struggling with depression. She is non-adherent, and her attachment scores are low.

The deficient nature of K and L's attachment relationships, as evidenced by their inability to recall their birth mothers' faces, or eye color, had a lasting impact. After spending the majority of their childhood with drug addicted mothers, they were the most depressed, and non-adherent. Also, they both had dropped out of school and were using substances.

Lost Siblings

In addition to lost birth mothers and fathers, five subjects lost contact with their siblings. Several subjects and caretakers told their stories. For example, one adoptive mother, who had close communication with the social worker and case worker who investigated the subject's medical neglect case and who decided to remove him from his birth mother's care, had quite a bit of information about the subject's early experiences with his older brother.

She stated,

> E's birth mother was addicted to heroin, and, she would not come home for days. E's older brother would knock on the neighbor's door to ask for a can of apple sauce. He would feed E the entire can, saving nothing for himself, and he would change E's diaper. He couldn't have been more then seven. He also took the brunt of their mom's verbal and physical abuse to protect E.

E's adoptive mother went on to explain that the subject's brother would spontaneously show up at their house for visits with his brother, but he lived with his birth mother, and he was worried about what the system would do to her, so he was secretive about where they lived. Eventually, the visits became less frequent. The adoptive mother admitted she thinks about E's brother "all of the time" because he was such a "sweet kid." E stated he missed his brother, "I think about him a lot."

K described her story. She explained,

> I lived with my older brother and my mom until I was eight. My brother is slow, and my mother did drugs, so we would live in and out of hotels, apartments, and cars. I didn't go to school very much, and my brother never went. She used to tell him he didn't have to go because he was dumb anyway. I remember watching her shoot up a couple of times in front of me and my brother. The one time I was truly happy was when she came home and made us food, and we were all together and we ate. It was the best feeling in the world. When I was 8 and my brother was 10, she took us to a shelter and left us there. I was adopted by this nice couple, but he wasn't. He had to go to a special home because he was slow. I feel so bad. I think about him all of the time. We tried to get together once, but it was really awkward, and now I am not sure how to find him. I feel so guilty that I got a family and a nice house in the suburbs and he never got anything. My mom was so mean to him.

The siblings that were lost to these subjects offered protection and company in the face of early neglect and trauma. Thus, E and K experienced an additional traumatic loss in relation to their siblings. The grief of a loss of a sibling and the survivor guilt which accompanies it, exacerbates symptoms of depression and causes resistance to adherence (Archer & Burnell, 2003).

Displacement

In addition to the categories of "lost birth mothers" and "lost siblings" another finding was the negative transference towards the medicines. Shame, secrecy, hate,

mistrust, the medicines as attacking and sabotaging, and sickness were feelings commonly attributed to the medicines by all of the non-adherent subjects.

The subjects blamed their feelings of difference on the continuous experience of having to take medicines. Over half of the subjects acknowledged the medicines as a constant interruption in their daily lives, which painfully reminded them that they were different. None of the subjects grew up knowing any other children (with the exception of the children in clinic), that had to take medicine two to three times a day, everyday. Many negative aspects of the virus were attributed to the medications by the subjects and their caretakers.

All of the subjects acknowledged that they grew up feeling like they were prevented from doing what other, "normal" children were doing because of the medicines. For example, they weren't able to go on overnights because they had to take their medicines along, which they had to hide from their friends who did not know their diagnosis.

Another example was participation in sports. Many subjects were told early on that they would not be able to play sports because they were sick and they had to take their medicines at certain times everyday, and therefore, they couldn't go to practice. Others were told that it was too dangerous for the other children to play with them because of the possibility injury which might expose the other children to their blood.

Some of the subjects and their parents chose to have gastro-intestinal-tubes inserted because administering large amounts of medicines orally was too difficult. Surgically, the G-tube was inserted into their abdomen, so the medicines could be administered directly into their system. However, going swimming was a problem for the

children with G-tubes because their friends would be able to see the G-tube through their swimming suit. This was certainly a problem for the subjects living in the inner city where most people who live without air conditioning spend the summer in the lake.

Also, if they were going anywhere for more then a few hours, they had to go home, pack up their medicines, and bring them along. For many, this was a problem because their friends and their friend's parents often began asking questions.

For all of the non-adherent subjects, the medicines were a daily manifestation of the shame which HIV carried. During their early and middle childhood years, all of the subjects were encouraged to keep their status a secret because of the stigma. Several of these subjects admitted to hearing people at school and in their neighborhoods talk about people who had AIDS with disgust and fear.

One subject, Y, said,

> I always heard people saying, that they would never be by someone with AIDS, and it's true. I had to leave my friends to go home to take my medicines, so I told some of my friends that I had HIV, and they didn't come by me anymore. Kids at school would run down the hallway screaming, "She's got AIDS! She's got AIDS!" It was horrible.

Another father stated, "Nobody ever knew she was sick. Even I had trouble remembering, that is, until I would have to give her medicines."

All of the subjects lived with this secret when they were growing up. For some, the only tangible evidence that they had the virus was the fact that they had to take medicines.

The compelling aspect about this finding was the extent and intensity of negative feeling the non-adherent subjects had displaced on to the medicines. One subject stated, "I am in special education because of the medicines." Another subject displaced his anger

about his birth mother onto the medicines, “I hate the medicines. I don’t feel like I should have to take them. I am not the one that gave me this disease. I hate them.” Yet, another subject stated, “I have no self confidence because of the medicines.” Another subject stated, “The medicine will kill you before the HIV does.” Two subjects stated, “I would rather not be here, than have to take medicines.”

Sixteen of the subjects complained about the “horrific” taste of the medicines and the ghastly way the medicines made them feel. Several subjects’ described not feeling sick until taking their medicines, which did not make sense to them as small children. They felt “great” until they took their medicines, which they were told would keep them alive, yet, after taking them, they felt terribly sick.

Regarding her medicines, one subject admitted to not believing the medical team. She stated, “I felt so healthy. I thought, there is no way I am sick. They made a mistake. I am not taking those medicines. They are the things making me feel sick.” Four subjects disclosed that they used the medicines to manipulate their caregivers. “They would feel sorry for me, so sometimes they would allow me not to take them. They babied me a lot because they felt sorry for me.”

One story a birth father told about his daughter highlighted the element of mistrust attributed to the medications. This father lost his wife to HIV/AIDS when his daughter, also diagnosed with HIV, was seven years old.

He said,

> Well, when A was eight years old they put her on new medicines and they told me to give her 8 milligrams of this one type of medicine. After I gave it to her, she said to me, “Daddy, I don’t feel good. I need to go to the hospital.” I had a bad feeling about this new medicine, so I put her in the car and went straight to the hospital.

> They took her right away, but they sent me home to get the medicine. While I was home rushing to get the medicine and get back to my baby, the nurse called and asked if it was ok if they gave her a blood transfusion. They gave her a 50% chance that she was going to make it because they gave me the wrong pill to give her.
>
> The wrong pill! And, I was supposed to give her more of it, but I didn't because the first time I gave it to her she got sick. So, if I had done what those doctors said the medicine would have killed my baby, and she's all I got left. I think whoever made that mistake made a bad mistake. She went seven days with that IV in her. I still think about it. I'm still thinking about if I have trust in the medicines. Sometimes, when I think about that day, I don't have much trust. I try, but I just don't.

A was one of the most non-adherent subjects, and has failed a HARRT regimen. She was put on the last regimen available to her at the time of this interview. Understandably, it was A's birth father who conveyed the strongest sense of fear that I had heard throughout the interviews. Perhaps it was because he was traumatized by his wife's violent illness and traumatic death, which he assumed was going to be his only daughter's fate. When asked about his daughter's feelings about her deceased mother he stated, "We don't talk about the past. The past will kill you. If you put all that bad into your memory bank, it will bust."

Death Sentence

This theme of fear was conveyed in 18 interviews. One adoptive father stated, "They told me it was death sentence. They gave her 'till three to live. It was terrifying not knowing whether she would live or die from one day to the next. It was like that for every kid in the clinic. It was a death sentence back then and everybody knew it."

One birth mother stated, "I couldn't deal with not knowing whether my son was going to live or die, so I got high." The same birth mother described her brother spending as much time as possible with Q, while she was out getting high. She said, "He thought

HIV was a death sentence and he didn't have much time with Q, so he spent every free moment he had with Q." Fear paralyzed many, but in this instance it motivated an uncle.

The majority of the subjects were predicted to not live beyond four years old, but they did. Yet, the toll that the prognosis took on their caretakers was undeniable. For example, one adoptive mother stated,

> He was always in the hospital. They were continually telling me they did not expect that he would live past five, so I was always bracing myself for the next hospitalization that would do him in. I decided that I had to be more of a nurse then a mom or else I would not have made it through what he did.

Over half of the caretakers of these subjects acknowledged that someone, somewhere along the line had given their children the prognosis of a very short life span.

The anxiety this produced in the caregivers was unintentionally communicated to the subjects because over half of the subjects acknowledged that they knew they were predicted to die. The subjects' affect around this issue seemed to be defensive and several subjects disclosed distorted thinking regarding the issue. For example, one subject stated, "I was supposed to die. I know I was, but I didn't, and I am not sick. So, that just makes me think I don't need the medicines." This invincibility is also a characteristic common in adolescents.

Found Birth Mothers

Another theme embedded in the qualitative data was "found mothers." There are two HIV infected mothers who were intravenous drug users when they gave birth to HIV infected children 15 and 16 years ago. They are alive and doing well today. They were both drug addicts who discovered their HIV diagnoses after they had given birth. Neither

of these women was able to cope with the idea that they had given a deadly disease to their child, so they both disappeared into the streets.

Shortly after the birth of their children, the women left their babies with their mothers. These grandmothers were loving and kind. Against the odds, the women committed themselves to getting clean and found their way back into their child's life. It should be noted that if these women had not had their own mothers to care for their babies and support their return to the family, they may have lost their babies to the system, and they may have lost the hope that they could return to the child without consequences.

Subject Q's birth mother stated,

> My mom was there through it all. When I couldn't even look at my child because I was so disgusted with myself, she held him, and loved him. She loved him so much. She didn't care if he had HIV. She didn't give it a second thought. She fed him, clothed him, bought his diapers, and took him to the doctor. She took care of him until I could.

The second mother stated,

> I left him with her, and she loved him like she was his own mother. She took care of him until I could get it together. She was a very special person. Before she died, she gave V dog tags. One tag is a picture of his father and the other is a picture of her. He has never taken those tags off. He wears them everyday. We miss her.

"How Did this Happen to Me and My Child?"

These mothers had to cope with their feelings of shame pertaining to acquiring the virus from their substance use and the transmission of the virus to their children. However, there were four mothers who had a different set of circumstances. Two of these mothers were alive to tell the stories, two were not. The following accounts describe the circumstances surrounding how these mothers and their children acquired the virus.

The first story was told by a birth mother who, currently, has a conflictual relationship with the subject, M. Reportedly, she was battered by her husband, the subject's father. M retold a memory, which his mother corroborated, of his father pinning her down a number of times. In one instance, his father held a knife to her neck. M was three years old and he stated, "I think I saved her because I cried and begged him to let her go and he did."

This birth mother began the interview by stating,

> I don't really remember a lot. I don't have good memories. I guess I block a lot of stuff out. I remember when he was six and they told me about his sickness. I was really sad. I cried so much. I thought, "How can this happen?" I don't use drugs. I've never used drugs, so how did this happen? They tested M at Norwegian Hospital. He had a high fever and a rash all over his bottom, so they ran a lot of tests. I didn't want to believe them, so I took him to another hospital for a second opinion, but it was true. He had HIV.

This mother did not test positive for the HIV virus, so it appeared M did not contract HIV at birth. He did not show symptoms until the age of six. Also, the subject was too old to have a rash around his bottom that could be explained by diaper rash. M's mother could not recall what kind of rash it was, but she acknowledged that it was the rash that prompted the hospital to test M for HIV at a time when HIV was uncommon in the pediatric population. M's father died of HIV/AIDS when the subject was ten years old. M's mother admitted that she had told her M that his father died from a "sudden asthma attack." She was emotional in the interview and when this interviewer inquired about how M could have acquired the virus, she stated, "I have no idea. It is a mystery."

Throughout the interview M's mother stated 4 times that M loved his father, and that, "His father was always there for him. He was a good and loving father. No matter what, his father was always there for him." She also stated, "He was always closer to his

father. He wanted to be with his father all of the time. He never wanted to be with me." She began crying, and stated, "M doesn't think I care or that I am a good mom. He doesn't respect me. Sometimes, I really think he hates me."

When M was interviewed, he stated that he remembered being told about the virus when he was 11 years old. He said,

> My mom, sister, nurse, and social worker told me. I didn't have no feelings because I already knew, but I didn't think it was a serious thing. Even when I found out I had it, I didn't believe I had it because I never felt weak. I never felt sick. I was a fighter. I've always been a fighter.

When M was asked about his feelings about his father, he stated,

> He was a good guy when he wasn't doing drugs, I know he was. I would always look up to him and I would tell him I wanted to be just like him and he would say, "No, don't be like me." I didn't understand why he would say that, but now I do, because of the drugs. He didn't want me to do the things he was doing. He used to talk about my mom, and he would say, she is a good lady. He would say, "I cry on the inside for what I've done." You know, because men don't cry. That's why I don't cry that much.

It was not evident how M contracted the virus at age six because his birth mother was not HIV positive. Two possible explanations were that M's birth father, who was HIV positive, either sexually abused M, which would explain the rash on M's bottom, or accidentally stuck M with a needle. This idea was highly defended against by M and his birth mother. Both M and his mother idealized M's father and his relationship with M.

The second subject, T, also acquired the virus mysteriously. T tested positive for the virus after his birth father had passed away of a drug overdose. T's mother told the story,

> It was a Saturday morning. T was four. His dad came over to visit while I ran out to get my hair cut. He lived in the same apartment building, so I would let him baby-sit for T and Kristin every once in awhile. Kristin was ten. Mostly, I left

> them with my mother, because I didn't trust their father, but I was only running out for an hour or two. When I came home, I found them both sitting together holding each other in a chair crying. T's father was lying on the sofa, he wouldn't wake up. I called 911 and they rushed him to the hospital. I didn't go with because I wanted to be with my kids because they were so scared.
>
> Somebody from the hospital called and told me that he had mixed heroin and cocaine and shot it up, which means he probably did it in front of the kids. They put him on a ventilator. He stayed in the hospital for 33 days until he died.
>
> After he died, his doctor told me that he had HIV/AIDS and that T and I should get tested. The test came back positive for both of us. I started taking him to the hospital clinic and I asked them to look up T's records because I was suspicious. His dad took him to the hospital when he was two years old because he had a rash and a fever. I was sick too, that is why his dad took him. They told me that they had a record in the computer that showed that his dad was informed that T had symptoms that were only symptomatic of HIV. He knew for two years before he passed away and he didn't say nothing. T doesn't know this story. He doesn't know how we got it.

When the subject was asked about how he acquired the virus. He said,

> When I found out I was so angry. I didn't know who to be angry at. I didn't know why or what. Now, I think it was because of my dad. I don't know. If the doctors would've known when my mom was pregnant, they could've taken me out early and I would've been fine. I just don't understand what happened. I don't understand. I mean, I am fine and I am proud of myself and I am looking forward to college, so I guess it is just something I need to get over.

The third story was difficult because there was little information offered. This subject, Z, was the most depressed subject out of the 20. Z identified that he thought he was "very depressed" during the interview. He was also passively suicidal during the interview stating that "I'm tired of living." When asked why, he stated, " 'cause I miss my mom."

After being asked about how he acquired the virus, Z responded, "I don't know. I don't remember at all. Obviously, I got it from my mom. I don't know anything else." His uncle who is one of his caregivers stated,

> His mom got HIV from her husband, but we don't talk about that. She was real smart, though. She had a couple of degrees and a really good job. She and my sister were really close. They were tight. She and her husband split up. She

> refused to have an abortion. She said, "Z might discover the cure for aids." She didn't know she was sick until after Z was born, though. Z always says he misses her.

When asked about his father, Z gave the same listless response he had given with his other answers, "I don't know. He died before I turned one. I guess he was a good guy. He died before my mom. I don't remember." The mystery surrounding the deaths of Z's birth parents seems to add to his ambiguous feelings about his own life and death.

The fourth narrative depicted another account of a woman and her baby, F, who were infected in an unusual manner. Her husband, F's biological father, tells their story,

> We did not discover her illness until F was a few years old… two or three abouts. Actually, her mother became ill and in testing her mother, we discovered F had HIV and myself. I would say that it had to be a very bleak, depressing, emotional period of time. F was so young. She (F's mother) got it from a needle stick at Rush, before universal precautions were in place. In the late 70s.

This statement was confusing considering the subject, F, was not born until the very late eighties.

When asked about what she knows about how she acquired the virus, F stated,

> I was 11 or 12 and I was confused. I didn't know anything about it (HIV). I started crying. I was mad and upset; I guess just that I had it. My dad and Amy (Step-mother) made me feel better. They are always trying to make light of things—joking and goofing around.

Interestingly, none of the subjects seemed preoccupied with how exactly they acquired the virus. They seemed more concerned with the fact that they had the virus and what it meant for them in that moment. This reaction may have been defensive, and was a way for the subjects to protect themselves from their anger at their parents or their feelings of helplessness.

Shared Memories

One of the most pronounced findings, although the most uncommon, was that of an early, shared memory between the caregiver and subject. There are three subjects who talked about a memory involving their caregivers with great detail and delight, which their caretakers also told with the same affect in their interview. Neither party had knowledge that the other had disclosed the same memory. It should be emphasized that these three subjects are adherent, the least depressed, and most attached to their caregivers.

This is an important finding because it is the shared meaning in an attachment relationship which solidifies the bond between caregiver and child, allowing the child to develop a cohesive sense of self, and supporting the child in co-constructing their own individual narrative. Shared meaning transforms into a shared memory (Huhes, 2003).

There are two shared memories told by T. T and his birth mother have been together since his birth. T's mother contracted the virus from her husband, T's father, who died of a drug overdose and HIV/AIDS complications when T was five years old.

T told this story,

> I remember when I was little, I got mad at my mom because she wanted me to stop playing and eat dinner. I didn't want stop playing, so I got mad, and took some of my mom's jewelry and threw it out the window. Kristin saw me do it and she was afraid I would get in trouble, so she ran downstairs with her marble collection and traded the marbles for my mom's jewelry because the neighborhood kids were playing outside and had already picked it up.
>
> I remember I watched her from the window, and I felt so ashamed. So, I went to my mom and told her what happened. I cried and my mom held me and told me how to feel better. She said a good way to pay Kristin back for her marbles was to do some of her chores for her. So, I did a lot of her chores that day and I felt a lot better. Kristin did too. My mom and me set up a lemonade stand the next day and traded lemon aide for her marbles. We got them all back. Isn't that funny?

The second memory he told was a story about a time when he and his sister went for a walk in their neighborhood. He said,

> When a group of boys walked past us and stopped to talk to my sister, I said to them, "Who are you and why are you talking to my sister? Then I looked at my sister, and she said to me, "T, they are in my class. I know them." And I said to them, "Okay, you can talk to her." Funny, I thought I was protecting her and I was just a little guy.

T's mother identified these stories as some of her favorite memories of T when he was little. She told these stories with similar detail and delight. She believed T was an extraordinarily bright toddler, and she remembered spending a great deal of time reading to him. She also remembered T talking in complete sentences by the time he was two. So, at the time, she says she was not surprised at T's precocious assertions of independence, but she was more proud that he showed feelings of remorse for his own actions, empathy, and love for his family at an early age.

The second subject, V, and his mother, independently retold a memory shared by them also. V said that he liked his bottle when he was little.

> I didn't want to let go of my bottle, so I would cry when my momma and grandma would try and take it from me. I got big, though, and I still wouldn't let it go. I was stubborn for a little kid. But, I was afraid of the dog next door. It was a big black dog that sounded mean when he barked. So, one time I couldn't find my bottle, and my grandmother and mom told me the dog next door got it. So, I never asked for it again. I wasn't going to mess with that big dog over my dumb bottle. It's funny now 'cause they were just teasing, but it worked. I loved my grandma. My mom and I loved my grandma.

This subject not only disclosed a memory which he shared with his mother, but his grandmother was also included in the memory. His grandmother was an important attachment figure in his life. The memory is shared between the three of them, and when he recalls the memory; his feelings about his attachment to them arose.

The third subject, H, and her caregiver described a memory that was shared. Her adoptive mother said during her interview,

> I didn't think the medicines were a big deal. I had never had problems with H taking her medicines, so when I saw the kids in the clinic with G-tubes, I was floored. I remember one time when H was two and a half, I was preparing her oral syringes like I did every morning, and she was in her chair and I went to give her the medicine and she grabbed the medicine from my hand and declared, "Me do it." And you know what, she did it her herself! I mean, of course, I had to help her a little bit, but after she was done I cheered, she cheered, and we cheered together. I told her she was such a "big girl." She was funny.

H told the same story, although slightly differently:

> I guess, I never thought the medicines were a big deal. My mom always had a way of making them less miserable. When I was really little, she would play this game with me, like challenging me to be a big kid and take my medicines on my own, and one day I said, "Me do it!" And I did. She got all goofy and silly and cheered like she was so proud of me. She made me laugh. Parents are so embarrassing.

These three subjects had the highest attachment scores and adherence scores. There was another subject, M, who had an early shared memory with his caregiver, but this memory was negative and traumatic. Although M was adherent he had a low maternal attachment score.

The memory related to his father who is now deceased.

> I was at the table eating cereal and my mom was getting ready to go to work. My dad came out of nowhere. He grabbed her and put a knife to her neck, screaming, "Mira! Mira!" …that means, Look, somebody's there. My mom was crying and I started crying and I begged him to let her go, and he listened to me. He let her go. I think I saved her life. I felt so sorry for my mom 'cause what she went through with him. He would beat her up every time he would get high. She would have black eyes and pulled out hair. I think we had a dysfunctional family.

His mother stated,

> This one time, his dad attacked me and held a knife to my neck, and M was crying and begging him not to hurt me. M brings it up to me all of the time. It is on his mind. He says, "I'll never forget that.

This memory is traumatic and intrusive for M. Although M was adherent, reportedly, he had gotten into a substantial amount of trouble for fighting at school and in the neighborhood, and had spent time in a detention center.

These shared memories represent shared meaning. This meaning making process occurs in the attachment relationship between caregiver and child and gives experiences definition and emotion. Through shared meaning, the child learns how to regulate affect (Bradley, 2000). This was apparent in the case of T. T felt ashamed and alone, and had difficulty tolerating these feelings, so he sought out his mother for comfort. She did not shame T, but instead soothed him by holding him and helping him find a way to ease his guilt. T internalized this ability and is able to cope with negative feelings when they arise as an adolescent. The inability to regulate affect, however, leads to the development of psychopathology (Bradley, 2000). Psychopathology interferes with an adolescents' ability to tackle age appropriate developmental tasks such as adherence.

Alive with No Memory

There were two subjects, Y and X who had not lost either birth parent. Neither of these subjects were adherent or has high attachment scores. Y had a high attachment score to her birth father, which was apparent in her interview. Although Y was able to recall several specific and positive memories of her father, she wasn't able to do the same with her mother, nor was her mother able to remember any positive experiences with Y.

Y had many fond memories of her birth father:

> When me and my brother and sisters were little my dad used to be in charge of our baths because my mom was too afraid of us 'cause we were little and fragile. My dad would put us all in the bath and splash and play with us. We would get him wet because we thought it was so funny.

> My dad is goofy, funny, and caring. He likes to cook, so he makes big breakfasts for us and we can pick whatever we want for breakfast. He used to have races with us in front of our house. We would take it so seriously at first, but then he would tackle us and we would get in a big heap and laugh and just lie there. He's funny at dances too. He puts on his silly hat and he dances all goofy. He is the one that makes me feel better when I am sad. He makes me laugh because he is so funny.

Conversely, Y talked plainly about her birth mother, and wasn't able to recall a specific memory of when they spent time together. The interview with Y's birth mother was short. Y's mother had a difficult time elaborating on her thoughts. In relation to Y, she stated, "She don't talk much to me, but I was always there for her, and I took care of her; food, clothes. She would never go to bed without eating." This response was interesting because Y's birth mother identified the biological needs that she had met for Y, but could not acknowledge any emotional or relationship needs between the two.

The interview with X's birth mother was similar. The interview was short, and X's birth mother was not able to elaborate on any questions about X specifically either. She acknowledged that she was a good mother because she had "fixed X food and gave her baths." She was able to talk vaguely about a memory of X when she was little; however, she wasn't able to elaborate. She stated, "I remember when X was ten months old, she got an infection and she had to stay in the hospital for 12 days. It was a bad time in my life. I was sick at the time also."

Similarly, X's interview was as short as her mothers. She was not able to identify any specific memory of her mother and father while she was growing up. Yet, she was able to talk about a family vacation that her family went on that she remembered very positively.

It should be noted that there was a possibility that these birth mothers were guarded with their information because they were ashamed of their situations. The medical team was suspicious that these birth mothers and one of the birth fathers in these families use substances to cope with their situation, which was an additional explanation for their inhibitions during the interview.

However, the compelling finding regarding these interviews was that the caretakers in these interviews were not able to remember anything specific about the subjects as they were growing up. There was no sharing of experiences or memories, which was a significant indicator that the attachment relationship was lacking. There is much evidence which supports the attachment relationship as the affective context which creates the structure of memory, allowing the child to regulate their own emotional experiences, co-construct their own narratives, and integrate a sense of self (Hughes, 2003). An unintegrated sense of self leaves an adolescent less capable to master difficult developmental challenges, such as adherence.

Early Attributions

Contrary to an attachment relationship which lacks shared meaning, there were several relationships in this study which exemplified a new mother's engagement in the attachment relationship, which may be a predictor of the child's future attachment style. (Cicchetti and Toth, 1998).

There are 13 interviews with caretakers, in which the caretaker described positive attributes about the child as an infant. These caretakers included adoptive mothers,

relative caregivers and foster parents. For example, one adoptive mother referred to her child as an infant as, "an old soul. There was something peaceful and wise about her."

An adoptive father said,

> They thought she would freak out when she left the hospital, but I knew she wouldn't. They put her in my arms, and I strutted out the door. Look at me and my fighter kid. When I got her home I told her she was home, and she let out a loud sigh, like 'hooray, I made it!'

A birth father said,

> They brought her to me and put her in my arms, and I started talking to her and she opened her eyes the minute she heard my voice. I think she was listening to me before she was born and when she heard my voice after she was born, she wanted to look and see who it was that had been talking to her all that time. She was a smart little thing.

The infants who suffered early attachment trauma and were taken out of their birth mother's custody, such as, B, and E, had new caretakers who read their cues when they were infants. B's foster mother said,

> When I first got him, he didn't cry or do anything. I said to myself, I know why he don't cry. Babies stop crying when nobody comes. So, when I got him, I held him and talked to him as much as I could to make up for that.

She understood his infantile experience and responded empathically.

E, the subject with the worst early attachment history, had an adoptive mother who understood his toddler wishes so insightfully that she did not send his birth mother away when she came to her door unscheduled and intoxicated. Not only did she allow his birth mother to rest at her home, but when she discovered this birth mother holding and cuddling her child, she did not interrupt. Another example is J's caregiver, who attributed a similar attachment need to J. "She grabbed a hold of my leg like, I am not letting go of this mommy. Oh, I'll never forget that. What a good baby."

Thirteen subjects had caregivers who were able to read their early cues for attachment, and respond empathically, which allowed for the birth of a new attachment relationship. There are seven subjects, however, who did not. Three of these subjects lived with their birth mothers until they were in middle childhood. These birth mothers were not alive to talk about their feelings about the subjects when they were infants. Three birth mothers were not able to say anything about the subjects as infants because they could not remember anything specific and one subject was placed with a relative who was not able to remember anything about the subject as an infant. The presence of early attributions indicates a positive start to the attachment relationship which can be a deterrent to depression and developmental lags.

CHAPTER V

DISCUSSION AND CONCLUSIONS

This study set out to understand the psychological components or meanings that the subjects attach to their medicines in order to gain a better understanding of the factors preventing them from taking their medicines. This understanding is imperative to their survival. Sixty five percent of this population is non-adherent. Well over half of these adolescents will get sick and die in the near future if clarity is not gained on this issue. This study hopes to provide some of that clarity.

When this study was proposed, it was hypothesized that the trauma resulting from early attachment disruptions, and the subject's current level of depression were two compounding factors causing non-adherence. Developmental conflicts were also thought to be a complicating factor. The findings of this study support this hypothesis, and highlight how and why attachment trauma and depression have a negative impact on adherence.

Depression

A statistically significant relationship was found between adherence and depression. There was a significant difference in the depression scores between the adherent and non-adherent subjects. The adherent subjects were less depressed $t = -2.103$, $p = .05$. This finding was consistent with the literature, which recognizes

depression as a contributor to poor adherence (Hosek et al., 2002; Rabkin & Chesney, 1999; Starace et al., 2002).

While the relationship between depression and adherence was established in this study, the specific results of the Beck's Depression Scale were surprising. Only one subject scored in the clinically significant range for depression. Yet, when the scores of the depression scale were compared with the data collected in the qualitative interviews, a more important finding emerged.

This finding was the second largest finding of the qualitative data, and involved the subject's desire to be "normal." All of the subjects reported strong negative feelings about feeling "different." Because the subjects were aware that their score would be viewed by a select group of people, I believe it was of paramount importance to the subjects to convey themselves as "normal" rather to answer the questions authentically.

This phenomenon was further supported by the qualitative data which indicated that many of the subjects disclosed symptoms of clinical depression in the interview, although they did not score in the clinical range on the Beck's Depression scale. Included in these disclosures were feelings of extreme hopelessness and passive suicidal ideation. It was this researcher's belief that the depression survey was an obvious tool which was slightly manipulated. An interpersonal interview, on the other hand, due to the length and intersubjective nature of the process, was more accurate in eliciting authenticity.

Attachment

A similar phenomenon occurred with the scores derived from attachment scale. There were several subjects whose high attachment scores on the attachment survey

contradicted the data collected in the qualitative interviews. The subject M exemplified this trend. M scored as securely attached to his deceased father. However, M's experience of parental death, and attachment trauma are critical in understanding his attachment style.

The loss of a parent is traumatic for any child, however, because many of the subjects in this study have experienced multiple traumas such as: abuse, neglect, attachment disruptions, and medical trauma, the loss of a parent is devastating psychologically (Bradley, 2000). In order to rid themselves of the intolerable affective states which trauma induces, children use several psychological defenses such as, identification with the aggressor, denial, and idealization (Archer and Burnell, 2003). These were the three psychic defenses which M employed.

M scored as securely attached to his birth father, who was abusive and violent. When M was very young his birth father repeatedly attacked, assaulted and threatened his birth mother in front of him. In the interview, M pardoned his father for these episodes stating, "My father did not mean it. It was the drugs."

However, it seemed that when M was a little boy, he escaped the intolerable feelings of powerlessness and terror by identifying and internalizing the part of his father that he experienced as powerful, aggressive and frightening. This identification with the aggressor, allowed him to avoid shame, and guilt by using power and control in relation to others (Archer and Burnell, 2003). It has been reported that M was aggressive at school, in his neighborhood, and in relation to his mother. M has also spent time in juvenile detention. M's defensive structure allows M to continually idealize his father, and his attachment relationship to his father, despite his father's past abusiveness.

In contrast to M, the subject N, who also lost a parent, described a safe and loving relationship with her adoptive mother. Although her adoptive mother passed away when N was young, N remembered and re-told many warm stories of her mother. N's attachment score was consistent with the data collected from her interview. She seemed more genuine and less affected by the psychological aftermath of her adoptive mother's death.

Attachment and Adherence

The most profound finding from the attachment data was all seven of the subjects who were adherent had, at minimum, one secure attachment. Six out of the seven adherent subjects had a secure attachment to at least one caregiver and four of these subjects had secure attachments to both caregivers. Five of the seven subjects reported a secure attachment to their maternal caregiver. Five of the seven adherent subjects also reported a secure attachment their paternal caregiver, and four report a secure attachment to their peers.

The subject who was adherent, but did not have a secure relationship with his maternal caregiver or paternal caregiver was a subject who endured brutal and relentless complications due to the virus. He had seven abdominal surgeries in one year and an organ transplant two years later. He was on 16 different medications to manage his HIV and his transplant. If he was not adherent to his medications, he would die immediately. Subsequently, his family is highly motivated to support him in maintaining his adherence.

An additional finding regarding attachment was the age at which the permanent caregiver took over care of the subject. There were seven subjects who were adopted in

infancy. These subjects were the most securely attached, but three disclosed depressed feelings during the interview and only two were adherent. The earlier the disruption in attachment occurs the better, but only if it is immediately replaced by a stable new opportunity for bonding. Additionally, there were a multitude of ongoing factors which played a role in the subjects' well being, including the subjects' own resilience, developmental conflicts, experiences of early medical trauma, and, most importantly, the quality of their old and new attachment relationships. Often, it was unknown what their experiences with trauma were before they were adopted. For example, two were hospitalized for several months after they were born because they were born addicted to heroin. Five had multiple placements until they were adopted.

The quality of attachment, however, seems to be the most significant predictor of the subjects' future well being. For instance, in infancy a child instinctually attracts their caregiver through a number of cues; eye contact, cooing, crying, and grasping. If the caregiver is consistently attuned, and responsive to the infant's negatively aroused states, the infant internalizes this experience of being soothed and becomes able to manage greater amounts of tension and arousal (Sroufe, 1979). Gradually, through this continued experience with their caregiver the infant develops and maintains internal security (Bowlby, 1969/1982).

This internal security transforms into an internal working model, which mediates the child's experience of interpersonal relationships and the feelings that go along with these relationships (Bowlby, 1980). They have the courage to engage with the world around them. Constantly exploring their surroundings, toddlers are continually trying to

master the difficult tasks of walking, talking, playing, and toilet training. (Bowlby, 1988; Davies, 1999).

However, when the infant does not develop trust and confidence in their caregiver because they have been neglected and left for very long periods of time in negatively aroused states, they do not trust that their mother will come to comfort them. They do not believe themselves to be safe in the world and many aspects of their development are arrested (Cicchetti and Toth, 1998). Infants left in this prolonged state of negative affective arousal develop psychological defenses in order to survive these unbearable states (Bradley, 2000).

These children perceived their caregivers as unavailable and rejecting, while simultaneously regarding themselves as unlovable (Cicchetti and Toth, 1998). Their capacity to regulate their own affect was stunted (Bradley, 2000; Cicchetti and Toth, 1998) In the worst cases, they withdrew from the world around them because they perceived it as an unsafe world in which nobody was trustworthy. It was these toddlers who grew up defensive about the world. They are insecure, hopeless, and angry. Their internal working models contribute to a depressive organization (Bowlby, 1988; Bradley, 2000; Cicchetti and Toth, 1998).

This was further exemplified by the findings pertaining to the subjects who lost their birth parents in toddler-hood. They were the most idealizing of their birth mothers, depressed, and the least emotionally attached to their caregivers.

The three subjects who lost their birth mothers in toddler-hood had insecure and avoidant attachment styles. E and P had drug addicted mothers who were neglectful and abusive. Z's mother discovered her diagnosis when he was a year and a half, and got sick

shortly after. She was in the hospital for a long period of time when Z was an infant. This attachment disruption occurred during pivotal infancy years and seems to have impacted Z's attachment style as devastatingly as the others.

From infancy to toddler-hood, the children whose caregivers were not able to remain consistently attuned and responsive in ways that soothed the child out of negatively aroused states, were the children with insecure or avoidant attachment styles (Bradley, 2000; Cicchetti and Toth, 1998). These toddlers became defensive to protect themselves from a dangerous world.

The defensive structure that an infant internalizes to maintain their attachment, despite the psychological pain which the attachment relationship causes, was discovered to be a paramount issue for the subjects in this study. Infants develop many pathological defenses which serve the unconscious goal of maintaining the longed for attachment.

One maladaptive defense which infants use when left in the unbearable sates of prolonged negative arousal is that of idealization (Bradley, 2000; Summers, 1998). Both idealization and omnipotence defend against the infant's helplessness and persecutory anxiety, resulting in the denial of all frustration and negative experience. Consequently, the ability to deny reality becomes another primary defense in this stage of development (Summers, 1998). Melanie Klein stated, "the idealized object is so massively defended against that dependence on other objects is denied and the only object relation is to the internalized idealized object with which the ego identifies." (Summers, 1998).

The story of E poignantly captured this infantile defense, and dramatically demonstrates the power of the first attachment and the yearning for it in difficult times. E was an infant continually left in intolerable states for long periods of time. He was

removed from his birth mother's custody at three years old, due to severe neglect, and he was placed with a loving adoptive family.

At age eight he entered the hospital and endured six consecutive surgeries, yet was faced with another. Psychologically, he could not bear anymore. Refusing to interact, he withdrew from the world. He refused to eat, make eye contact, and speak. He was listless and withdrawn. However, when his birth mother, whom he had not seen in years, came to visit, E came back to life. Within moments of her visit E was laughing, chatting, and playing games with his birth mother. After she left, E was able to tolerate another life saving surgery. E's massive desire for his birth mother obliterated all the negative feelings he had about being abused and neglected, and he maintained a fantasized attachment to her. Despite having a loving adoptive mother, his birth mother was the only one who could soothe him. As the devalued object, his adoptive mother was left powerless to soothe him in a life and death situation.

An additional factor which played a role in the extent of pathology apparent in the subjects who lost their birth mothers in toddler-hood, was their experience of medical trauma. For instance, these subjects were diagnosed in infancy and experienced countless medical procedures, both invasive and non-invasive, in addition to being required to continually ingest horrific tasting medicines in very large quantities. One of these subjects had seven consecutive invasive surgeries at the age of eight, and an organ transplant a few years later. The physiological pain, fear of death, and intrusive invasions of their bodies have undoubtedly, left their mark on these subjects (Hughes, 2003).

The presence of an attachment figure throughout traumatic experiences is a hugely protective factor (Hughes, 2003). Unfortunately, in E's case, his birth mother

could not support him through the majority of his medical traumas. Similarly, Z, and P had mothers who were very ill and drug addicted, so it is unclear whether they were available to offer consistent reassurance when their child was suffering from medical trauma.

The two subjects who lost their birth mothers in their middle child-hood were equally as depressed, extremely non-adherent, but not as idealizing of their birth mothers. They disclosed angry and sad feelings about their birth mothers' state while they were growing up. These subjects were able to talk about the anger they felt when they remembered how their mothers used to shoot heroin in front of them and their siblings, left them for days without food, and abused their siblings. However, neither subject could remember their mothers' face or the color of her eyes. They each remembered their mother's hair color and tattoos, but could not recall their mothers' facial features. One subject stated, "Up until I found out she was dead, I was always thinking I would pass her on the street and not even know it was her."

Developmentally, within a secure attachment relationship, an infant is able to recognize their mother's face as early as four to six months. Infants may not have the capacity for configural processing, but they can differentiate their own mother through her eye size and hair line (Ascerra, Burnod, & De Schonen, 1999). The literature indicates that infants of depressed or substance abusing mothers are less able to recognize their mothers face (Reif, Field, Diego, Ruddock, 2006).

This finding was significant because it was evidence that in adolescence there were still numerous signs of the quality of the subject's early attachment relationship.

One of the most important indicators of the quality of an early attachment relationship was the shared memories between subject and caregiver.

Shared Memories

There was much evidence which supported the attachment relationship as integral in building the social matrix of memory, allowing for the development of an awareness of self (Hughes, 2003). Through shared conversations and experiences with primary attachment figures, the child co-constructs their own coherent story or narrative (Hughes, 2003). The attachment relationship provides a powerful emotional milieu and structure for the child's first memories. The relationship also helps mediate and integrate the sensory, motor and linguistic templates necessary for encoding individual information, from which the child derives an increasingly integrated sense of self (Hughes, 2003). Without the experiences of shared memories within the attachment relationship, the child has a deficient sense of self (Hughes, 2003).

The four subjects and caregivers who, independently of each other, told the same detailed and positive memory of an early shared experience was a strong indicator of the positive quality of their attachment. These four subjects were the most attached, least depressed, and most adherent.

There are two adherent subjects who also re-told positive early memories of their birth mothers, however, their mothers are deceased, so it was not absolutely clear if the memory would have been shared. Both of these subjects had fathers who indicated that their wives shared the same fond memory. If these are included then six out of the seven adherent subjects have and can articulate positive shared memories with their attachment

figures. This finding, perhaps, was the most conclusive because it supported the quality of the attachment relationship as a predictor of adherence.

Early Attributions

One important indicator regarding shared memories and the quality of attachment between subject and caregiver were the attributions the caregiver bestowed upon the subject early in their attachment relationship. The maternal caregivers who were not able to recall the positive attributions they had bestowed upon their infant were indicators that, perhaps, that they did not have positive attributions in relation to their child. Depressed and substance abusing mothers have a much higher rate of communicating negative attributions to their child (Cicchetti and Toth, 1998).

In addition, depressed mothers seem to convey significantly more negative affect in their attributions in regards to the child's feelings. Unfortunately, this leads to poor self esteem, self awareness, and depression in their children (Bradley, 2000 and Cicchetti and Toth, 1998). The caregivers who attributed positive characteristics to the subject as an infant developed the strongest attachment relationships with the subjects, and shared the same positive memories of the subject growing up.

Negative Transference towards the Medications

It was clear that the attachment findings were paramount in understanding the psychological structure from which these subjects operated. The intense feelings of shame resulting from attachment difficulties may have compelled these subjects to resort to a primitive defensive structure which allowed them to psychologically rid themselves

of intolerable feelings by projecting them onto a psychological object. The first and most dependable defense mechanism in infancy is projection (Summers, 1994).

The entirety of this defensive structure pivots on the delineation of the world into good and bad objects exclusively, and is referred to as the paranoid position. Clearly, the medicines seem to be psychologically categorized as a bad object for many of these subjects. The subjects who were non-adherent lacked the stable sense of self and operated from a pathological and defensive position, which warded off painful feelings by psychically splitting them off and projecting them onto psychological objects (Summers, 1994).

The negative transference the subjects had towards the medications was also understood as displacement. Displacement is the projection of intense feelings onto a less threatening object because the object who would otherwise be the recipient of these feelings is too threatening (Summers, 1994). For example, M was fearful he might be retaliated against if he had intensely angry feelings towards his father who had abused him in the past, so M displaced his feelings onto his mother, who was passive and non-threatening.

This pathological defensive structure was the result of trauma in the infantile developmental stage when good and bad objects are integrated into the ego (Summers, 1994). Attachment complications and painful secrets are experiences which induce powerful feelings of shame (Bradley, 2000; Hughes, 2003; Summers,1994). For instance, unfulfilled longing for love in early attachment relationship results in feelings of shame, and a rejecting or neglectful attachment figure compels a child to feel unlovable, and that their own love is bad (Summers, 1994). The subjects' knowledge that their

physical love was dangerous to others may have also intensified feelings of shame and elicited a sense of self hate.

As a receptacle and container for this self hate, the medicines became the bad object for the non-adherent subjects. Unfortunately, the dynamics of the medical situation perpetuated the medicines as the bad object. According to medical personnel when they discover evidence of non-adherence, they confront the subjects' caregivers in an attempt to assist them in resolving the issues.

Reportedly, the caregivers and subjects often became defensive and angry at these challenges. In addition, rumors of child protective services involvement circulate in the clinic when the medical team has no other alternative but to file a medical neglect report on a parent. According to medical personnel, the child and parent often align to protect each other regarding the medicines. Medical personnel are perceived by some caregivers and subjects as threats because of their position of authority and power to intrude with regard to controlling behavior around medications.

Developmental Considerations

Developmental factors also contributed to the medicines as the "bad object." The non-adherent subjects in this study attributed all of their negative feelings about their situation to the medicines. Many of these reasons were understandable such as, the stringent, three times a day; medicine regimens which interrupted and prevented them from being with their friends, in addition to the nausea and vomiting which sometimes accompanied the medicines and imprisoned them at home. Also, the medicines

represented a shameful secret which they could not share, which acted as a road block to the intimacy they longed for with their peers.

In adolescence, the desire to be liked and accepted by peers is paramount. Peer acceptance is critically important in adolescence. Being accepted enhances self esteem and self confidence, so adolescents dedicate themselves to making sure their appearance, interests, and values match that of the peer group they have selected. They seek constant approval from this peer group (Rothenberg, 1990). Consequently, peer acceptance and peer relationships are at the heart of adolescents' developmental needs. Adolescents do not want to feel different unless it is in an attempt to individuate and separate from their parents. Subsequently, taking medicines and having close friends were conflicting forces in the subjects' lives. Developmentally, it is understandable that these subjects chose fitting in with their friends over taking their medicines.

Yet, there were seven subjects who were able to adapt to taking medicines despite the irritations they caused in their teenage lives. Six out of the seven adherent subjects had healthy attachment styles from which a stable sense of self arose. Because of this stable sense of self, these subjects were able to work through developmental conflicts with the support of their caregivers. They trusted that the medicines were important to their well being. One adherent subject stated, "I don't like 'em, but them keep me alive." Another subject said, "They are a pain, but I am used to it now. They keep me out of the hospital." The adherent subjects were able to integrate the negative and positive aspects of the medicines which allowed them to progress developmentally.

What seems to be true from the data is that the quality of the subjects' attachment style predicts their ability to be adherent to the medications. The age at which the

caregivers began caring for the subjects and the nature of their early attachment relationships, determines the subjects' enduring attachment styles. Early and positive attributions bestowed upon the subjects by their caregivers in infancy, and the presence of early shared memories during the subjects' childhoods, indicates the positive quality of their attachment relationships.

Statistically Significant

Along with statistically significant relationship found between adherence and depression, $t = -2.103$, $p = .05$, the attachment data also revealed an unanticipated statistically significant finding. This finding was the correlation between the subject's quality of paternal attachment and the quality of peer attachment**:** $r=.566$, $p < .01$. As the score for paternal attachment rose, so did the score for peer attachment. This relationship seemed logical if viewed in the context of child psychological development.

The adolescent years are informally considered the second phase of separation and individuation, toddler-hood being the first. In adolescence, the attachment relationship to caregivers becomes more diffuse, and their relationships with their peers becomes more intimate (Rothenberg, 1990). Adolescents spend less time with their parents and more time with their peers. They confide in their peers and obtain their attachment needs; need for emotional closeness, met through their friends as opposed to primarily through their caregiver (Cicchetti and Toth, 1998; Rothenberg, 1990).

Long before adolescence, the first phase of separation and individuation occurs. In early toddler-hood, the dyadic relationship between caregiver and child is interrupted by the child's awareness of the importance of a third party. This third party is sometimes

the child's birth father, and sometimes it is whoever the mother is in a close relationship with. The child's awareness of the third party creates rivalrous feelings within the child, and fear that he/she will be retaliated against for having these feelings. Simultaneously, the child is discovering his/her own erogenous zones, which colors this phase with a libidinal energy. Fearing the powerfulness of the third party in comparison to the child's own powerfulness, the child represses these wishes, and feelings of guilt and shame arise. This was described by Sigmund Freud as the oedipal complex (Gay, 1989; Summers, 1994).

Other theorists disagree with the notion that guilt and shame are products of this phase. They conceptualize the infant's unsatisfied libidinal desire as an internalization of an accepting object (maternal) and a rejecting one (paternal). This psychic constellation then allows the infant to defend itself against the demands of object love through repression and inhibition (Summers, 1998).

This process is also referred to as self-awareness and self-other differentiation. The introduction and development of a second important relationship, diffuses the primacy of the child's relationship with their mother, forcing the child to become aware of another. The development of autonomy, the emergence of the affect of shame, and the construction of an internal representational model of the self and the self in relation to others are essential in toddler-hood (Cicchetti and Toth, 1998).

Subsequently, the existence of a third party or father who supportively promoted the self-other model during the first separation and individuation phase in toddler-hood, better prepared the child, psychologically, for the second phase in adolescence (Cicchetti and Toth, 1998). If the child successfully internalized a sense of self awareness and self-

other model, they have the psychological apparatus to do the same in their adolescent years. Therefore, the significant data relating paternal attachment to peer attachment is important.

Conclusion

In conclusion, a healthy attachment relationship protects the adolescents from being overwhelmed with negativity and the need to create a defensive structure that distorts reality and prevents them from taking their medicines. The quality of this attachment relationship was captured by the positive attributions bestowed upon the subject by the caregiver and the shared meaning the subject and caregiver created together.

Limitation of the Study

The limitation of this research plan was the small sample size. The small sample size was not sufficient to identify statistically significant relationships that may exist. This project, however, was a substantial beginning effort in researching this problem. The data that were collected will assist mental health professionals and medical professionals in understanding how HIV infected adolescent's behavior is impacted by psychological factors. The potential for designing interventions that could, ultimately, impact the health, well being, and survival of chronically ill adolescents is great.

Implications of the Study

Because attachment complications were a strong predictor of non-adherence in this population, it is important for social workers and medical personnel to recommend that the future caregivers of these children participate in psychotherapy early on. Psychotherapy, more specifically, play therapy, would help the child work through the complex traumas associated with inadequate attachment relationships, invasive medical procedures, and past experiences of abuse and neglect. The caregiver may also participate in the child's psychotherapy and together they will strengthen and reinstitute a healthier internal working model of attachment within the child.

In addition, because adopting and fostering a child with attachment issues is difficult emotionally, the caretaker may benefit from engaging in individual psychotherapy or a support group for adoptive and foster parents who share similar experiences. Although, many pediatric clinics who specialize in treating children with HIV offer support groups for both the caregivers and children, these groups focus on the difficulties of coping with HIV. Because a child's attachment style is the foundation from which they cope with daily stressors, the child's psychological issues involving attachment and complex trauma need to be addressed earlier and independently in psychotherapy.

However, by the time the child reaches adolescence, a support group comprised of HIV infected adolescents would assist the adolescents in gaining empathy for each other and themselves. They would feel less isolated and more connected. This group might be scheduled before or after clinic as a function of the medical visit.

If the caregiver adopts or fosters the child in middle childhood or adolescence the importance of engaging the child in their own psychotherapy is equally important. Family therapy is also strongly recommended to support the child and family in coping with the new family dynamic that an additional family member brings about. The peer support groups which are offered by many of the HIV clinics who care for these children, as mentioned above, are critical in middle childhood and adolescence in normalizing the child's condition, and allowing them to feel close, safe, and connected to their peers.

As in the case of E, it is important for the adoptive/foster parents to de-center and avoid taking the child's rejecting attachment behaviors personally. E's adoptive parents accepted his inability to get close or show affection, but found still ways to supportively interact with and care for E.

The medical personnel who treat these children and families should be aware of the triangulation which a defensive caregiver and child resurrect in response to a challenge to their self esteem. The caregiver-child dyad often feels challenged when the medical personnel confronts them about issues of non-adherence. At this moment when the medical personnel feels the caregiver or child becoming defensive, they should steer away from the concrete evidence which points to non-adherence, and their focus should become supportively interpreting the caregiver and child's defensiveness, and the painful fears of guilt and shame underlying it. Interpreting these feelings when appropriate and empathizing with the caregiver and child will help diffuse their defensiveness which may allow them to accept the support and assistance offered regarding adherence.

Alternatively, if the focus remains on the evidence of non-adherence, a continuous and relentless power struggle will emerge which inevitably leads to the

medical team's acknowledgement that it is a medical neglect issue. Of course, the medical team then has solidified themselves as the bad and threatening object in the caregiver-child's eyes and the enactment has been allowed to come full circle. On the other hand, supportively interpreting the feelings underneath the defensiveness will allow for an empathic and supportive relationship to develop between caregiver-child and the medical team, which allows the medical team the ability to help with the complicated issue of non-adherence.

Future Research

Future research exploring the neurologic and cognitive impact of complex trauma on children with HIV is necessary. Antiretroviral medications can be toxic and may also impact a child's neurologic and cognitive functioning. Gathering data on these two factors may assist medical personnel in finding ways to compensate for cognitive and learning deficits as the children progress developmentally.

Additional research on the sharing of shameful secrets in adolescence would also help these children. Adolescents are self conscious and consumed with feelings about how and what other people think of them. In order to gain the true intimacy they long for with their peers and romantic partners, adolescents may need to share a shameful secret; yet, adolescents are ill equipped to master such a sophisticated and complicated task. Additional research and literature on the subject may help parents, caregivers, social workers and medical personnel support the adolescent with such an endeavor.

APPENDIX A

PACTG 219C PEDIATRIC ADHERENCE QUESTIONNAIRE

PACTG 219C PEDIATRIC ADHERENCE QUESTIONNAIRE MODULE 1

Behavior/Identification

NIAID PEDIATRIC AIDS CLINICAL TRIALS GROUP

Patient Number [ ][ ][ ] [ ][ ][ ][ ] Date of Patient Visit [ ][ ][ ] [ ][ ] [ ][ ][ ][ ]
mmm dd yyyy

Protocol Number [2][1][9][C][ ][ ] Institution Code [ ][ ][ ][ ][ ][ ]

Form Week [ ][ ][ ] * Seq No. [ ] ** Step No. [ ][ ] Key Operator Code [ ][ ][ ]

* Enter a "1" if this is the first of this form for this date. Designate subsequent forms on the same date with a 2, 3, etc.
**Enter the subject's current study step number. Enter '1' if the study does not have multiple steps.

The **purpose** of this questionnaire is to collect data which will quantify the proportion of prescribed antiretroviral therapy actually taken within the last 3 days in order to examine drug effect. In order to have confidence in the data that will be collected with this instrument, the **process** through which these data are collected has been **standardized**. Please read and observe the following directions. Medications taken daily are recorded in question 5. Medications taken on a three times a week, weekly or monthly schedule are recorded in question 6.

Who administers? Any member of the professional clinical care or research team who has experience filling out other ACTG study forms.

Who is questioned? The research subject, if the subject has assumed responsibility for his/her own drug regimen OR the subject's primary caregiver (the person responsible for administering the prescribed drugs at home). If the appropriate respondent is the primary caregiver and she/he is not present for a particular study visit when this form is scheduled, the forms should be marked as such (below) and the assessment omitted.

How is the questionnaire administered? The questionnaire has very specific introductory comments (and prompts) which should be read as stated, item after item, until the assessment is completed. No interruptions for patient education should occur; any necessary or additional education or counseling should take place after the questionnaire is completed.

The accuracy of self report is very good if the attitude of the interviewer is non-judgemental and supportive. The form has introductory statements to set this tone. However, since information about erratic adherence may be elicited by the survey, what interaction happens after the questionnaire is completed is critically important. The attitude of the clinical response, the manner in which information is subsequently corrected, and the nature of behavioral counseling will **absolutely** influence future validity. It is imperative that clinical teams review the characteristics of therapeutic relationships and strive to adopt these practices in promoting drug adherence in study subjects.

QUESTIONS 1 - 4 ARE TO BE COMPLETED BY THE STUDY NURSE:

1. Was the questionnaire completed at this visit? .....(1-Yes, 2-No) [ ]
   If Yes, go to question 2.
   If No, complete 'a' and STOP.

   a. Indicate the reason the questionnaire was not completed:..... [ ]
   1-Subject refused
   2-Primary caregiver refused
   3-Subject missed clinic visit
   4-There was not enough time
   5-Primary caregiver not available
   9-Other reason, specify

   If Other, specify [30]: _____

2. Who responded to the questions?.....1-Subject [ ]
   2-Biological mother
   3-Biological father
   4-Other relative, specify
   5-Adoptive parent
   6-Foster parent
   9-Other, specify

   If "4-Other relative" or "9-Other", specify [30]: _____

Pt. No. ☐☐☐☐☐☐☐ * Seq. No. ☐ ** Step No. ☐☐ Date ☐☐☐ ☐☐ ☐☐☐☐
mmm dd yyyy

3. Does the subject know his/her HIV status?..... (1-Yes, 2-No, 3-Information not available/Not known) ☐

4. Since the last visit, did the subject utilize any of the following aids for improving adherence?..... (1-Yes, 2-No) ☐
   If No, go to question 5.
   If Yes, complete 'a - n'.

(1-Yes, 2-No, 3-Not Known)

a. Labels..... ☐
b. Calendars..... ☐
c. Pill boxes..... ☐
d. Beepers..... ☐
e. Monitoring caps (MEMS)..... ☐
f. Timers..... ☐
g. Programmable wrist watches..... ☐
h. Diary..... ☐
i. "Buddy system"..... ☐
j. PEG/gastrostomy tube: ..... ☐
k. NG Tube: ..... ☐
l. Central Line: ..... ☐
m. Activity of daily living triggers: ..... ☐
   Specify [30]: _____
n. Other: ..... ☐
   Specify [30]: _____

Pt. No. ☐☐☐☐☐☐☐☐ * Seq. No. ☐ ** Step No. ☐☐ Date ☐☐☐ ☐☐ ☐☐☐☐
mmm dd yyyy

5. **INSTRUCTIONS FOR COMPLETION OF DAILY MEDICATION TABLE:**

- **Columns A-D:** Prior to the study visit, the study nurse should fill in the information in these columns for **each antiretroviral and prophylaxis medication** that the study subject is prescribed.
- **Column A:** List the drug name (if known or, if double-blinded study, as marked on bottle).
- **Column B:** List the eight digit drug code for the drug listed in Column A. Refer to Appendix 3 or the Drug Code Lookup Program at the DMC Web Site (http://www.fstrf.org).
- **Column C:** List the drug color, type (blue pill, pink liquid, etc.) and note any special identifying labels.
- **Column D:** List the expected number of **doses** per 24 hour period. This refers to the **schedule** (eg. 3 times per day, 4 times per day) and **not** the number of pills. Particulars of the schedule will not be addressed (eg. TID and q 8 hr would both be recorded as 3 times per day.).
- **Columns E-I:** This information is to be obtained from the study subject or primary caregiver in the subsequent interview.

DAILY MEDICATION LIST TABLE: Do not key Column C.

NOTE: Go to question 6 for medications that are on a three times a week, weekly or monthly schedule.

[1] Identification Codes	[2] Doses Missed
1-Volunteered without prompt 2-Volunteered with prompt 3-Acknowledged when reminded 4-Did not acknowledge	Enter "-1" if subject isn't sure if he/she missed any doses. Enter "0" if no doses were missed.

Complete Prior to Visit				Complete During Interview				
A	B	C	D	E	F	G	H	I
						Doses Missed[2]		
Drug Name(s) [30]	Drug Code	Drug Color, Type and Labels	Expected # Doses	ID Code[1]	Reported # Doses	Yesterday	2 days ago	3 days ago
a.			☐☐	☐	☐☐	☐☐	☐☐	☐☐
b.			☐☐	☐	☐☐	☐☐	☐☐	☐☐
c.			☐☐	☐	☐☐	☐☐	☐☐	☐☐
d.			☐☐	☐	☐☐	☐☐	☐☐	☐☐
e			☐☐	☐	☐☐	☐☐	☐☐	☐☐
f.			☐☐	☐	☐☐	☐☐	☐☐	☐☐
g			☐☐	☐	☐☐	☐☐	☐☐	☐☐
h.			☐☐	☐	☐☐	☐☐	☐☐	☐☐

When was the last time you missed any of your HIV medications?
__ within past week
__ within past month
__ within past 6 months
__ never

APPENDIX B

SEMI-STRUCTURED QUALITITATIVE INTERVIEW WITH CARETAKER

Semi- Structured Interview with Caretaker

These questions are about what you know of your child's early experiences. They are about your child's early history and the people that took care of them during the first five years of their lives. This person might be you, depending on your relationship with the child, and when you began taking care of them (you might be the birth mother or father, foster mother or father, relative, or adoptive mother or father). Your child might also have had more then one person who took care of him/her during their first five years, as many of their birth mothers and fathers have passed away. Also, you might have started taking care of the child after they turned five years old, so if you cannot answer the questions because you don't have any knowledge of their experiences before you started taking care of them, that is ok. These questions may make you uncomfortable because they may be about you and your child. The interviewer will go slow and stop at anytime if you indicate the questions are too difficult.

1. Do you know who took care of your child from birth until your child was 5 years old?
2. Can you tell me about each caretaker and what you know of them?
3. Do you know about any specific early experiences your child had with any and all caretakers (this includes birth mother and father, relatives, foster and adoptive parents)?
4. Has your child re-told an early memory about an early caretaker (this may be you)?
5. Do you know of any stories or favorite memories a caretaker may have conveyed to you about their child before you took over their care?
6. If your child's birth parents have passed away, do you know how he coped with their loss?
7. Does your child ever talk about wishes to be with an earlier caretaker?
8. Does your child have any favorite pictures or items given to them by an early caretaker?
9. What do you think your child would say about their early caretakers? If it was you, what do you think your child would say about his\her early experiences with you?

APPENDIX C

SEMI-STRUCTURED QUALITATIVE INTERVIEW WITH THE ADOLESCENT

Semi Structured Qualitative Interview
With The Adolescent

These questions are about what it was like for you with the people who took care of you before you turned five years old. These people might include your birth mother and\or father, foster mother and\or father, relatives, and adoptive mother and\or father. These early experiences include your memories, thoughts and feelings. Some of these questions might be difficult to answer because it was a long time ago, and it may be hard to remember, but just try to do your best. The interviewer will go slow and give you as much time as you need to answer the questions. If you can't answer the question because you do not remember that is ok. Also, if you did not have a good experience with the people that took care of you when you were little, the questions might be uncomfortable to talk about. The last two questions are about your feelings about taking medicines. The interviewer will try to be sensitive to your feelings and stop to allow you some time for yourself if you need it. The interviewer will also provide you with a support person to talk to if the questions become too upsetting. Again, the interviewer will stop, if you feel that the questions are too uncomfortable to answer.

1. Is your birth mother still alive?
2. Do you live with her currently?
3. How long have you lived with her?
4. Do you have an earliest memory of your birth mother?
5. Can you tell me about it?
6. If you had to describe the kind of person your birth mother is/was, how would you?
7. Do you remember having a good or difficult relationship with your birth mom?
8. Did your mother pass away before you turned 5 years old?
9. Do you remember how old you were when she passed away?
10. Do you remember how you felt?
11. Do you miss her? If so, tell me how you feel when you miss her.
12. If your birth mom was alive today, would you have a good relationship?

13. Have you ever lived with anyone else? If so, who and for how long?
14. Did you have a foster mother or adoptive mother before you were 5 years old?
15. If you had to describe the kind of person your foster or adoptive mother was, how would you?
16. Do you remember who else you lived with until you were 5 years old?
17. Can you recall a time when the person taking care of you helped you feel better when you were upset?
18. Did they help you feel better a lot?
19. Who was good at helping you feel better?
20. How would they help you feel better?

21. Do you remember who told you your diagnosis of HIV?
22. Who was present when you were told your diagnosis?

23. Do you remember how you felt when you were told?

24. Is your father still alive?
25. How would you describe your father?
26. What is your earliest memory of your father?
27. Do you remember a time when he made you feel better when you were upset?
28. Do you have a favorite memory of your father? If so, tell me about it.
29. Do you remember how old you were when he passed away?
30. How did you feel?
31. Was there anyone able to help you feel better when he passed away?

32. How do you feel about taking medicines?
33. Can you describe all of the feelings you have about taking medicines?

APPENDIX D

INVENTORY OF PARENT AND PEER ATTACHMENT (IPPA)

INVENTORY OF PARENT AND PEER ATTACHMENT (IPPA)

Authors:
©Gay C. Armsden, Ph.D. and Mark T. Greenberg, Ph.D. [1]

This questionnaire asks about your relationships with important people in your life; your mother, your father, and your close friends. Please read the directions to each part carefully.

Part I

Some of the following statements asks about your feelings about your mother or the person who has acted as your mother. If you have more than one person acting as your mother (e.g. a natural mother and a step-mother) answer the questions for the one you feel has most influenced you.

Please read each statement and circle the ONE number that tells how true the statement is for you now.

	Almost Never or Never True	Not Very Often True	Some-times True	Often True	Almost Always or Always True
1. My mother respects my feeling.	1	2	3	4	5
2. I feel my mother does a good job as my mother.	1	2	3	4	5
3. I wish I had a different mother.	1	2	3	4	5
4. My mother accepts me as I am.	1	2	3	4	5
5. I like to get my mother's point of view on things I'm concerned about.	1	2	3	4	5
6. I feel it's no use letting my feelings show around my mother.	1	2	3	4	5
7. My mother can tell when I'm upset about something.	1	2	3	4	5
8. Talking over my problems with my mother makes me feel ashamed or foolish.	1	2	3	4	5
9. My mother expects too much from me.	1	2	3	4	5
10. I get upset easily around my mother.	1	2	3	4	5
11. I get upset a lot more than my mother knows about.	1	2	3	4	5
12. When we discuss things, my mother cares about my point of view.	1	2	3	4	5
13. My mother trusts my judgment.	1	2	3	4	5
14. My mother has her own problems, so I don't bother her with mine.	1	2	3	4	5
15. My mother helps me to understand myself better.	1	2	3	4	5
16. I tell my mother about my problems and troubles.	1	2	3	4	5
17. I feel angry with my mother.	1	2	3	4	5
18. I don't get much attention from my mother.	1	2	3	4	5
19. My mother helps me to talk about my difficulties.	1	2	3	4	5
20. My mother understands me.	1	2	3	4	5
21. When I am angry about something, my mother tries to be understanding.	1	2	3	4	5
22. I trust my mother.	1	2	3	4	5
23. My mother doesn't understand what I'm going through these days.	1	2	3	4	5
24. I can count on my mother when I need to get something off my chest.	1	2	3	4	5
25. If my mother knows something is bothering me, she asks me about it.	1	2	3	4	5

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Part II

This part asks about your feelings bout your father, or the man who has acted as your father. If you have more than one person acting as your father (e.g. natural and step-father) answer the question for the one you feel has most influenced you.

	Almost Never or Never True	Not Very Often True	Some-times True	Often True	Almost Always or Always True
1. My father respects my feelings.	1	2	3	4	5
2. I feel my father does a good job as my father.	1	2	3	4	5
3. I wish I had a different father.	1	2	3	4	5
4. My father accepts me as I am.	1	2	3	4	5
5. I like to get my father's point of view on things I'm concerned about.	1	2	3	4	5
6. I feel it's no use letting my feelings show around my father.	1	2	3	4	5
7. My father can tell when I'm upset about something.	1	2	3	4	5
8. Talking over my problems with my father makes me feel ashamed or foolish.	1	2	3	4	5
9. My father expects too much from me.	1	2	3	4	5
10. I get upset easily around my father.	1	2	3	4	5
11. I get upset a lot more than my father knows about.	1	2	3	4	5
12. When we discuss things, my father cares about my point of view.	1	2	3	4	5
13. My father trusts my judgment.	1	2	3	4	5
14. My father has his own problems, so I don't bother him with mine.	1	2	3	4	5
15. My father helps me to understand myself better.	1	2	3	4	5
16. I tell my father about my problems and troubles	1	2	3	4	5
17. I feel angry with my father	1	2	3	4	5
18. I don't get much attention from my father.	1	2	3	4	5
19. My father helps me to talk about my difficulties.	1	2	3	4	5
20. My father understands me.	1	2	3	4	5
21. When I am angry about something, my father tries to be understanding.	1	2	3	4	5
22. I trust my father.	1	2	3	4	5
23. My father doesn't understand what I'm going through these days.	1	2	3	4	5
24. I can count on my father when I need to get something off my chest.	1	2	3	4	5
25. If my father knows something is bothering me, he asks me about it.	1	2	3	4	5

Part III

This part asks about your feelings about your relationships with your close friends.
Please read each statement and circle the ONE number that tells how true the statement is for you now.

	Almost Never or Never True	Not Very Often True	Some-times True	Often True	Almost Always or Always True
1. I like to get my friend's point of view on things I'm concerned about.	1	2	3	4	5
2. My friends can tell when I'm upset about something.	1	2	3	4	5
3. When we discuss things, my friends care about my point of view.	1	2	3	4	5
4. Talking over my problems with friends makes me feel ashamed or foolish.	1	2	3	4	5
5. I wish I had different friends.	1	2	3	4	5
6. My friends understand me.	1	2	3	4	5
7. my friends encourage me to talk about my difficulties.	1	2	3	4	5
8. My friends accept me as I am.	1	2	3	4	5
9. I feel the need to be in touch with my friends more often.	1	2	3	4	5
10. My friends don't understand what I'm going through these days.	1	2	3	4	5
11. I feel alone or apart when I am with my friends.	1	2	3	4	5
12. My friends listen to what I have to say.	1	2	3	4	5
13. I feel my friends are good friends.	1	2	3	4	5
14. My friends are fairly easy to talk to.	1	2	3	4	5
15. When I am angry about something, my friends try to be understanding.	1	2	3	4	5
16. My friends help me to understand myself better.	1	2	3	4	5
17. My friends care about how I am feeling.	1	2	3	4	5

	Almost Never or Never True	Not Very Often True	Some-times True	Often True	Almost Always or Always True
18. I feel angry with my friends.	1	2	3	4	5
19. I can count on my friends when I need to get something off my chest.	1	2	3	4	5
20. I trust my friends.	1	2	3	4	5
21. My friends respect my feelings.	1	2	3	4	5
22. I get upset a lot more than my friends know about.	1	2	3	4	5
23. It seems as if my friends are irritated with me for no reason.	1	2	3	4	5
24. I can tell my friends about my problems and troubles.	1	2	3	4	5
25. If my friends know something is bothering me, they ask me about it.	1	2	3	4	5

APPENDIX E

BDI–II

BDI®-II

Date:

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

0 I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2. Pessimism

0 I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3. Past Failure

0 I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4. Loss of Pleasure

0 I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.
3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0 I don't feel particularly guilty.
1 I feel guilty over many things I have done or should have done.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

6. Punishment Feelings

0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7. Self-Dislike

0 I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

8. Self-Criticalness

0 I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. Crying

0 I don't cry anymore than I used to.
1 I cry more than I used to.
2 I cry over every little thing.
3 I feel like crying, but I can't.

_____ Subtotal Page 1

Continued on Back

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11. Agitation

0 I am no more restless or wound up than usual.

1 I feel more restless or wound up than usual.

2 I am so restless or agitated that it's hard to stay still.

3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.

1 I am less interested in other people or things than before.

2 I have lost most of my interest in other people or things.

3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.

1 I find it more difficult to make decisions than usual.

2 I have much greater difficulty in making decisions than I used to.

3 I have trouble making any decisions.

14. Worthlessness

0 I do not feel I am worthless.

1 I don't consider myself as worthwhile and useful as I used to.

2 I feel more worthless as compared to other people.

3 I feel utterly worthless.

15. Loss of Energy

0 I have as much energy as ever.

1 I have less energy than I used to have.

2 I don't have enough energy to do very much.

3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0 I have not experienced any change in my sleeping pattern.

1a I sleep somewhat more than usual.

1b I sleep somewhat less than usual.

2a I sleep a lot more than usual.

2b I sleep a lot less than usual.

3a I sleep most of the day.

3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.

1 I am more irritable than usual.

2 I am much more irritable than usual.

3 I am irritable all the time.

18. Changes in Appetite

0 I have not experienced any change in my appetite.

1a My appetite is somewhat less than usual.

1b My appetite is somewhat greater than usual.

2a My appetite is much less than before.

2b My appetite is much greater than usual.

3a I have no appetite at all.

3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.

1 I can't concentrate as well as usual.

2 It's hard to keep my mind on anything for very long.

3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.

1 I get more tired or fatigued more easily than usual.

2 I am too tired or fatigued to do a lot of the things I used to do.

3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex.

1 I am less interested in sex than I used to be.

2 I am much less interested in sex now.

3 I have lost interest in sex completely.

15 16 17 18 19 20 A B C D E

_____ Subtotal Page 2

_____ Subtotal Page 1

_____ Total Score

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