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MATERNAL HIV INFECTION AND PERINATAL TRANSMISSION:
Psychological Impact of Offspring Health Status

by

Ilona Kay Harris

A dissertation submitted to the Graduate Faculty in Psychology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York.

1999

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Abstract

MATERNAL HIV INFECTION AND PERINATAL TRANSMISSION:
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Ilona Kay Harris

Adviser: Professor Steven Tuber

Despite the fact that most women infected by HIV are of childbearing age, little research has focussed on the psychological interaction of motherhood and HIV. This study aimed to examine four areas of psychological impact of offspring serostatus on HIV infected women: use of denial as a psychological defense, characteristic affect level, identification with and assessment of offspring, and subjective sense of disease process. The Thematic Apperception Test, semantic differential tests, a drawing task and a semi-structured interview were used to assess women in each of these domains. Four groups of ten women each comprised the sample for this study: 1 - HIV infected women with infected children (II), 2 - HIV infected women with uninfected children (IU), 3 - HIV infected women with both infected and uninfected children (IIU), and 4 - uninfected women with uninfected children (UU). Findings supported a

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link between offspring serostatus and maternal defense use. Offspring serostatus was not shown to impact on participants' level of affect maturity; the generally low level of affect maturity among all participants was, however, noteworthy. Identification of women with their children appeared to be related to offspring serostatus based on interview data though not according to quantitative measures. Evaluations of offspring by their mothers were linked to serostatus; the children of women in the II group were evaluated most positively. Subjective sense of disease process also was linked to serostatus of offspring; compared with participants in the other groups, women in the IU group considered themselves the most affected by disease. Findings suggest that members of the IU group may have difficulty in mobilizing defenses sufficient to sustain hope; these women may be at particular risk for low self esteem and depression. This work also suggests that members of the II group use denial to a degree that may impair rational decision making in two areas: use of contraception and compliance with medical regimens.

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INTRODUCTION

The number of women worldwide who are infected with the human immunodeficiency virus (HIV) is rapidly increasing. Most of these women are of childbearing age. Burgeoning as well are the numbers of children born to HIV infected women. Without treatment during pregnancy, 15% to 30% of the children born to these women will themselves be infected with the virus (Caldwell & Rogers, 1991; European Collaborative Study, 1994; Gabiano, 1992; U.S. Department of Health and Human Services, 1987). The experiences of HIV infected women and their children -- their thoughts, feelings, relationships and hardships -- though frequently noted, have been, as of yet, little examined. This work focusses on the question of how HIV infected women are affected by whether or not their children are likewise infected. Some of the ways in which HIV infected mothers of infected children may differ from similarly infected mothers of uninfected children will be considered.

After a brief introduction to the HIV virus, its epidemiology, transmission, and symptomatology, I will address the question of whether there are, to date, any models which may help to elucidate the experience of these HIV infected women as they mother their children and cope with their disease.

The World Health Organization (WHO) estimated in 1990 that 8-10 million people had been infected by the AIDS virus.

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Approximately one third of these people (3 million) were women (Boyer, 1993; Chin, 1990; Oxtoby & Gayle, 1990; Reidy, Taggart & Asselin, 1991). According to the WHO, there are approximately 6000 people infected with HIV every day; nearly half of these are women. By the year 2000 the WHO estimates that between 30 and 40 million people worldwide will be infected with HIV, 13 million of them women (Blake, 1995). Centers for Disease Control surveillance data indicate that in the United States 80% of the women diagnosed with AIDS are of childbearing age, as are 90% of women with HIV. (Centers for Disease Control [CDC], 1994a). Most, especially in the United States and other industrialized countries, are from the poorest, most disadvantaged and disenfranchised groups (Boyer, 1993). In the United States the cumulative incidence of AIDS is 16 times higher for Black women and 7 times higher for Hispanic women than it is for White women (CDC, 1995). Although these groups account for under 20% of women in the United States, 77% of women diagnosed with AIDS are Black and Hispanic (CDC, 1995). A vast majority of these HIV infected women and their families are economically disadvantaged, often living in inadequate housing, receiving funds insufficient to meet basic needs, unemployed and un or under-insured (Albritton, 1990; Caldwell & Rogers, 1991; Canosa, 1991; Hankins, 1990; Ickovicks & Rodin, 1992; Pizzi, 1992; Spiegel & Mayers, 1991; Tiblier, Walker & Rolland, 1989). Certainly, few are in a position of sufficient economic stability to

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encounter any life-threatening illness without becoming overwhelmed merely by the financial and physical demands.

Globally, heterosexual transmission predominates as the mode of acquisition of HIV among women. In the United States and other industrialized countries the sharing of contaminated needles for intravenous, illegal drug injection contributes significantly to the spread of HIV infection to reproductive age women (Boyer, 1993; Gayle & Selik, 1990; Hankins, 1990; Landesman, 1989; Meyers & Weitzman, 1991). According to CDC surveillance data from July 1993 through June 1994, 48% of women diagnosed with AIDS in the United States reported the use of injection drugs (CDC, 1995). Many of the infected women in this country then are not only struggling economically against tremendous odds, but are those whose life-style is indicative of an existence peripheral to, and censured by, social structures that might otherwise lend support. They are by and large women whose self-esteem is low and who are often isolated from family and friends (U.S. Department of Health and Human Services, 1987; Wiener, 1991). In short, the women most often infected by the HIV virus are among those who are most vulnerable and least able to shoulder the burden of a chronic and eventually terminal disease.

As would be expected given the statistics on transmission of the AIDS virus to women in the United States, in this country approximately 50% of children acquiring HIV infections vertically (i.e., intrauterine, intrapartum, or postpartum

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transmission) are born to mothers with a history of intravenous drug use (IVDU) (Albritton, 1990; Amman, 1991; Spiegel & Mayers, 1991). The remainder of pediatric cases is primarily attributable to women who have been sexual partners of HIV positive men, mostly IVDU's (CDC, 1993). The most common mode of transmission for pediatric HIV infection is vertical. In the United States, 89% of children who are infected with HIV acquired the virus either in utero or perinatally (i.e., from the mother's bloodstream during pregnancy, with the virus travelling across the placenta -- or at birth)(Burroughs & Edelson, 1991; Caldwell & Rogers, 1991; CDC, 1994a; Meyers & Weitzman, 1991). A small percentage of children apparently acquired the virus during breastfeeding (Lambert, 1993; Oxtoby, 1990; Ziegler, Cooper, Johnson & Gold, 1990). The remainder of infected children acquired the virus from contaminated blood products with a few cases of transmission through sexual abuse. Screening methods for the blood supply in this country have already become more sophisticated, as is reflected in statistics revealing the decline of contaminated blood products as a mode of transmission for the AIDS virus (Caldwell & Rogers, 1990). Hence, the proportion of children infected perinatally can be expected to rise.

The percentage of children who are born to women infected with HIV and acquire the disease vertically, is, as noted above, between 15% and 30% when the mother has not received

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antiretroviral treatment during pregnancy. The administration of Zidovudine (ZDV - formerly AZT) during pregnancy has recently been found to lower the rate of perinatal HIV transmission to approximately 8% (CDC, 1994b). This finding could mean a decline in the numbers of children infected with HIV. Such an outcome requires, however, knowledge of HIV infection among women prior to pregnancy, easy access to prenatal care, and compliance with medical recommendations. Given these obstacles, for the time being, a considerable risk of perinatal HIV transmission remains.

An HIV infected woman may bear an infected child or children, and then an uninfected one, or vice versa. The factors determining whether the virus will or will not be transmitted during pregnancy and delivery are not yet entirely clear although there has been much preliminary investigation and speculation (Caldwell & Rogers, 1991; Canosa, 1991; Lambert, 1993; Oxtoby, 1990). One factor that has made the determination of rate of maternal transmission of the HIV virus particularly elusive is difficulty in diagnosing an infant as HIV infected during the first year of life. A child of an HIV positive mother will be born with passively acquired HIV antibodies, that is, maternal antibodies to the AIDS virus which have crossed the placenta. Thus, antibody detection tests on the baby will be positive, however, not all of these children are, in fact, infected with the virus. These maternal antibodies generally disappear by 6 to 12 months of

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age, at which point a clearer diagnostic assessment can usually be made on the basis of antibody presence. (Amman, 1991; Caldwell & Rogers, 1991; Levenson & Mellins, 1992; Oxtoby, 1990; Rogers, 1990). Although most children who are born with maternal antibodies to the HIV virus serorevert (i.e., lose those antibodies) and are uninfected, there are some cases of children who seroreverted but were later found, in fact, to be infected by the virus (Caldwell & Rogers, 1991). Moreover, delay and even absence of antibody production in some infected children has been reported (Borkowsky, Paul, Bebenroth, Krasinski, Moore & Chandwani, 1987; Gabiano, et al., 1992; Pahwa, et al., 1986; Tovo, et al., 1992). Due, then, to all of the above factors, diagnosis of HIV infection in infants on the basis of HIV antibody status is problematic. Use of the Polymerase Chain Reaction (PCR) test to detect presence of virus rather than antibody, has recently become more widespread (Amman, 1991; Pizzo, 1989). While questions as to the sensitivity, specificity and limitations in clinical situations of the PCR have begun to be addressed (Rios, et al., 1993), application of the PCR continues to be limited by its high cost, technical difficulty and limited availability (Palumbo, 1994). Recent advances in diagnostic assays promise the determination of infection status in "virtually all" infants by the age of 2-3 months. Such assays may be widely available at reasonable cost within a few years (Palumbo, 1994). Currently, in most cases a

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definitive diagnosis is established via laboratory indicators by six months of age. Some children who are infected with HIV become symptomatic before this time which itself may lead to clinical diagnosis.

The period from HIV infection to the onset of AIDS symptoms is known as the incubation period. Although recent studies suggest that true latent infection is rare and that subtle immunological indications may be evident, infants usually appear well clinically for the first several months of life. The incubation period in children is variable and seems to have a bimodal distribution. The first peak appears at between four and six months of age, and the other, revealing a much longer incubation period, at approximately six years. While there are some children who have remained asymptomatic for over eight years, (Amman, 1991; City and County of San Francisco, 1989; Oxtoby, 1990; Peckham & Newell, 1990), most children infected perinatally do develop clinical manifestations of the disease by about 3 years of age (Caldwell & Rogers, 1991; U.S. Department of Health and Human Services, 1987). According to the CDC (1994c) 50% of infected infants develop symptoms of HIV prior to their first birthdays, and 70% develop symptoms by age 2. In a European Collaborative Study (1994), 23% of perinatally infected children developed AIDS by one year of age and 40% by four years. Overall, the incubation period for children is much shorter than it is for adolescents and adults, few of whom

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develop symptoms of AIDS within four years of exposure to HIV. The median incubation period for adolescents and adults is approximately ten years (Oxtoby, 1990). Consequently, it is not uncommon for an infected and symptomatic baby to be a mother's first indication as to her own serostatus (Hankins, 1990; U.S. Department of Health and Human Services, 1987).

The incubation period of HIV in children is shorter than in adults, and the progression from mild to severe illness more rapid (Amman, 1991; Oxtoby, 1990). Mortality among symptomatic HIV infected children is highest in the first year of life (Arras, 1990). In 1989 the median survival time for children acquiring HIV perinatally was, according to Krasinski, et al. (1989), 1.87 years; and 25% of pediatric patients died within the first year of developing an HIV associated illness. The use of antiretroviral and prophylactic medications for infants and children has begun to lengthen survival time. According to a 1994 European Collaborative Study, 10% of children infected with HIV perinatally die within their first year; 28% within five years. Tovo (1992) reported a median survival time among such children of just over 8 years. Such medications seem to lessen symptomatology, improving growth rate, immunologic functioning, and, in many cases reversing the effects of AIDS encephalopathy (Amman, 1990; McKinney, 1991; Mayers, 1991; Oxtoby, 1990; Pizzo, 1989; Rogers, et al., 1989; Zuckerman, Metrou, Bernstein & Crain, 1991). The ongoing testing of

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combinations of different antiretroviral medications holds out the hope of enhanced efficacy with an alleviation of toxic side effects. The advent of antiretroviral and prophylactic medications, and their apparent, though limited, successes have increased the urgency for rapid, definitive diagnoses in infants and children.

HIV acts primarily through causing dysfunction and depletion of the cells that are central to coordinating the body's immunologic response to infections. Thus, many of the clinical manifestations of HIV infection in both children and adults are the consequences of an impaired immune system (Amman, 1991; Oxtoby, 1990; Oxtoby & Gayle, 1990). In addition, HIV's direct infection of the central nervous system (CNS) gives rise to various neurologic symptoms collectively referred to as AIDS Encephalopathy (Zuckerman, et al., 1991). The most common diseases observed in patients with AIDS are viral, fungal and parasitic opportunistic infections and malignancies. There is some variation in the frequency of symptomatology exhibited in children, men and women. Children tend, in the period prior to full blown opportunistic infections, to experience more bacterial infections than do adults. Infections commonly reported in HIV positive children include otitis media, sepsis and meningitis. Kaposi's sarcoma has only rarely been reported in either children or women. Women are more likely to suffer from gynecological manifestations of the disease such as cervical dysplasia;

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persistent pelvic inflammatory disease; amenorrhea; chronic Candida vulvovaginitis; and a number of sexually transmitted diseases (Boyer, 1993; City and County of San Francisco, 1989; Ickovicks & Rodin, 1992; Minkoff, 1989; Oxtoby & Gayle, 1990). One common opportunistic infection in both adults and children is Pneumocystis carinii pneumonia (PCP -- a parasitic pneumonia) (Krasinski, et al., 1989; Minkoff, 1989; Simonds, Oxtoby, Caldwell, Gwinn, & Rogers, 1993). This is a leading cause of death in young HIV infected children (Krasinski, Borkowsky & Holzman, 1989). After diagnosis of PCP the median survival time in a cohort of 3665 children with perinatally acquired AIDS was 19 months (Simonds, et al., 1993).

Both adults and children may suffer from "prodromal" signs and symptoms, that is symptoms of HIV infection which precede the development of the opportunistic infections, malignancies or neurological manifestations which are used to diagnose AIDS. Some of the clinical manifestations of HIV infection in young children are similar to those appearing in adults; others are dissimilar (Amman, 1990; Oxtoby, 1990). Signs and symptoms of disease which typically develop in young children include: failure to thrive; recurrent or persistent thrush (oral candidiasis -- a fungal infection); chronic lymphoid interstitial pneumonitis (LIP -- an inflammatory reaction in the lungs); hepatosplenomegaly (enlarged liver and spleen); chronic or recurrent diarrhea; lymphadenopathy (swollen lymph nodes); parotiditis (swollen, inflamed parotid

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gland); fever; and mild to severe developmental delay (Amman, 1991; Burroughs & Edelson, 1991; City and County of San Francisco, 1989; Oxtoby, 1990; Oxtoby & Gayle, 1990; Peckham & Newell, 1990; Rogers, 1985). In adults the prodromal period is characterized by weight loss, fever, malaise, night sweats, chronic or recurrent unexplained diarrhea, fatigue, generalized lymphadenopathy, arthralgia (joint pain) or myalgia (muscle pain), Cytomegalovirus, and oral candidiasis (City and County of San Francisco, 1989; National Institute of Allergy and Infectious Diseases, 1994; Oxtoby & Gayle, 1990; Rogers, 1985).

Thus, the spectrum of clinical abnormalities in patients with HIV infection may range from none to multisystem involvement. Clearly, though, the kinds of symptoms that an HIV positive mother will be faced with, either sooner or later, in both herself and in her child, may be severely debilitating, requiring hospitalization or extensive home care. The symptoms are often visible and not easily avoidable.

In summary, the women most directly and negatively affected by the epidemic in this country are, by and large, minority women of child bearing age. Many are or were at one time IVDU's. They generally have few social supports, and lack political, financial, medical and emotional resources. And most of these women will suffer from some of the disease's severe manifestations which may be both debilitating and

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demoralizing.

What then might the experience be like for these women? As Susser writes, "Families with AIDS are potentially dealing with the death of their child, their own illness and possible death, financial and medical crises, social stigma, isolation and lack of emotional support" (in Bor, 1990, p.409).

The literature has recognized some of the multiple and various stressors with which affected families must cope (Mellins, & Ehrhardt, 1993). Some authors have acknowledged, in general terms, the magnitude of the problems facing families in which more than one member is in need of medical, social and psychological assistance. Among the concerns that Septimus and Rubinstein (1989) identified as often pivotal in such families are: trauma and fears experienced by young adults losing their children; isolation and rejection from family members and friends causing the deterioration of couple and family relationships; full spectrum of uncontrolled emotions due to fatal illness -- hopelessness, depression, and suicidal ideation; guilt in infecting loved ones and fear of infecting further; pervasive anxiety related to future pregnancies in young women; anxiety related to lack of financial support, sexual involvement, medical outcome; and the need to plan for bereavement and the future of survivors.

Reidy, et al. (1991) comment on the difficult nature of a mother caring for a child when, "she herself is frightened of being sick or is already sick and facing frequent

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hospitalizations" (Reidy, et al., 1991, p. 331-2). They describe the unique and terrible circumstances of these women noting that they must,

> ...simultaneously come to terms with the sick role as well as that of caregiver and parent of a sick child. This double burden, personal and familial, increases the magnitude of their reaction to the illness. In sum, they must cope with the diagnosis of an HIV infection in not just themselves but also in another member of their family (Reidy, et al., 1991, p.341).

Despite their identification of the difficulties inherent in this "double burden," these authors do not explore in any detail the complex psychological repercussions that must ensue when the ill mother is caring for a child to whom she has transmitted HIV. The literature to date investigates comprehensively neither the experiences endured, the coping mechanisms employed, nor the psychological responses of HIV infected mothers.

To some extent, the assumption has been that models of parental anticipatory grief developed with regard to diagnoses of cancer in children adequately describe the experience of mothers who have children infected with HIV. These models did, in fact, evolve at a time when treatment options for childhood cancer were much more limited than they are today, and when, therefore, cancer in children was nearly always fatal. Moreover, some authors have commented on the

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similarities between HIV infection in children and other chronic childhood illnesses, noting particularly the extent of uncertainty regarding prognosis (Meyers & Weitzman, 1991). Indeed, Reidy, et al. (1991) report that the emotional reactions and needs of caregivers of HIV infected children are believed to be similar to those of parents of children suffering from other fatal diseases such as cancer. The caregivers differ in some crucial respects, however. The combination of the mother's ill health or anticipated ill health and the "possibility of either sociocultural divergence from the cultural mainstream or of a high risk life-style," as Reidy, et al. (1991) note, are two such differences -- and two which cannot reasonably be overlooked. Additionally, the HIV infected mother with an infected child differs from the mother of a child who has cancer in another vital respect: the HIV infected mother has, herself, transmitted the illness to her child and bears the burden of that knowledge.

Though the models that evolved to describe the ways in which parents of children diagnosed with cancer responded to the crisis have serious shortcomings when applied to HIV infected mothers, they are useful nonetheless. These very shortcomings alert us to some of the many unique aspects of the experience of HIV infected mothers.

Quite a number of studies set out to describe the experiences of parents faced with the life-threatening illness and death of a child. Most studies were based predominantly

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on observations of mothers. Although individual studies may be criticized for questionable methodology, in so far as most relied primarily on informal observation of small samples, the combined effect of the array of studies -- all reporting remarkably similar findings -- is quite impressive. These studies have two primary foci: first, a description of the various stages of anticipatory grief noted in the mothers, and second, the factors that seem to be associated with adequate maternal adjustment after the death of a child (referred to as "post-death" adjustment).

The period of anticipatory grief is one in which the patient and family, according to Sourkes (1982), flow between relatedness and letting go. This period tends to be accompanied by a profound sense of loneliness. When the loss is perceived as inevitable, grief is expressed in advance (Sourkes, 1982). According to Rando (1984), the normal components of anticipatory grief include, sadness, depression, anxiety, sorrow, anger, and a search for meaning.

The pattern of parental experience described during the period from the diagnosis to the death of a child (assuming the illness lasts at least four months) begins with denial, shock or a sense of being stunned, a feeling of utter disbelief. This is commonly succeeded by guilt, and feelings of helplessness and hostility often expressed toward hospital care providers. There follows a period of deep sadness, an experience of grief and then finally a reconciliation, a

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detachment and a reinvestment of energy and attention into other events and family members. The trend then, described in varying terms, is that of disorganization and denial moving toward a synthesis and reconciliation. Authors describe few "abnormal" grief reactions and in general, note a calm acceptance when death finally arrives (Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1965; Bornstein & Klein, 1974; Chodoff, Friedman & Hamburg, 1964; Friedman, Chodoff, Mason & Hamburg, 1963; Futterman & Hoffman, 1973; Gogan, O'Malley & Foster, 1977; Natterson & Knudson, 1960; Richmond & Waisman, 1955; Slavin, 1981) Natterson and Knudson (1960) depict this pattern as a "Tri-phasic" response moving from denial (including blatant identification of mother with her child and "intolerable" pain) to efforts to prolong the child's life (including a clinging to hope) and moving then, with a gradual decrease in expectation of survival to a final phase of separation from the child and sublimation of interest in the disease into "scientific" concerns -- i.e. more objectified. "In general," write Natterson and Knudson, "ego strength and breadth were markedly greater in the third than in the first phase" (p.463-4).

Although Gogan, et al. (1977) note a variety of definitions of "coping" over the years with no "clear, behaviorally-oriented, testable definition" (p. 44) as yet developed, there has been some consensus in the above mentioned literature, as well as in some more recent works,

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as to the kinds of "coping mechanisms" employed by the parents of children who have a life-threatening illness. There has also been some consensus as to the efficacy of these methods. Kaplan, Smith, Grobstein and Fishman (1973) argue that comprehension of the reality of a situation is essential to the initial parental coping task. Attempts to master the threatening reality cannot be successful, they argue, if psychological protection in the form of strong denial/avoidance keeps parents from comprehending their true situation. Others agree that excessive defensive measures can jeopardize optimal care of children or prevent the accomplishment of parental anticipatory grief work (Chodoff, et al., 1964; Futterman & Hoffman, 1973; Friedman, et al., 1963; Kaplan, Grobstein & Smith, 1976; Lowenberg, 1970). Futterman and Hoffman (1973) suggest a specific set of tasks they view as necessary for successful coping. Included among the tasks are the following: maintaining confidence, maintaining emotional and interpersonal equilibrium, reorganizing of life goals and activities, and anticipatory mourning.

Chodoff, et al. (1964) note that most parents are, in fact, able to function effectively during a child's illness. They are, that is to say, able to function "without being overwhelmed by despair or anxiety at the same time preserving their own personalities, maintaining key relationships and a measure of self esteem" (p.743). These authors describe

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denial as pervasive to some degree among the parents considered, and report that primarily it is utilized to sustain some small measure of hope. They report as well that motor activity (such as taking frequent walks) often functions as an adaptive defense. Less commonly they witnessed the projection of anger and resentment toward nursing personnel, minor somatization, absorption with medical minutiae, overeating, and avoidance reactions. One final point of some importance here is their observation as to the frequency of restitutive efforts accompanying the increasing feeling of detachment from a child. During the terminal phase of their child's illness, many parents conceived another child (See Shapiro, 1994).

Rando (1983) confirms the salutary effects of anticipatory grieving for parental adjustment after the death of a child. She cites some conditions which are associated with its occurrence. Among these conditions, Rando notes the importance of emotional support of caring friends or relatives. Also, some "optimal" amount of participation in the care of the hospitalized child is vital. Rando (1983) reports as well that having suffered prior losses and coping with many problems external to the ill child, adversely effect parental "post death" adjustment. Moreover, Deasy-Spinetta and Spinetta (1981) add to this the observation that, "Throughout the literature findings consistently illustrate that open family communication and explicit confrontation of

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anxieties surrounding the illness result in better adaptation to the illness by the child and family" (as quoted in Rando, p. 375). Finally, several authors have noted the important role of clear and honest communication between parents and medical staff for parental adjustment (Lascari & Stehbens, 1973; Stehbens & Lascari, 1974).

Important to note here is the impact of culture on parental anticipatory grieving and grieving patterns as well as on coping mechanisms and styles (Comas-Diaz & Griffith, 1988; De Spelder & Strickland, 1987; Lawson, 1990; McGoldrick, Pearce & Giordano, 1982; Shapiro, 1994). Certainly the responses noted above were, at least to some degree, culturally specific. The samples studied in the above investigations were predominantly White and Protestant with little variation. Thus, some of the differences we may note between the parents described in these models and the mothers of HIV infected children could well be attributed, at least in some measure, to cultural differences.

Given what we know about the lives of the majority of HIV infected women, it is certainly difficult to imagine how such a woman could fare well if these models do, in fact, point to important determinants of good post-death adjustment. Comparing HIV infected mothers' life circumstances and experiences with these models though, can certainly help to identify and clarify the nuances of their experience.

Clearly the HIV infected mothers of HIV infected children

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are ill prepared in terms of these factors which are presumed to assist in healthy adjustment to the death of a child. These women, by and large, are without significant emotional support, either internally or externally. Living with an often deep reluctance to tell anyone their diagnosis -- lest they be judged negatively and rejected -- more than in any other illness, HIV infected people tend to become isolated from others (Britton & Zarski, 1989; Kubler-Ross, 1987). An HIV infected woman generally abides external stresses of the most intense and basic kind: namely, constant worry over money, food, shelter, clothing, and other necessities including health care for herself and her child. Additionally, her own likely declining health may mean that she is physically ill prepared to meet all of these concerns. Participation in her hospitalized child's care and communication with health care providers may be limited both by her own quite reasonable fears of a judgmental, fearful, or hostile response from hospital staff as well as by her own physical limitations (Britton & Zarski, 1989). And, many of these women have suffered multiple prior losses (of, for example, loved ones, financial stability, social connections, health, home, etc.).

In addition to faring quite poorly on the factors thought to assist with parental adjustment to a child's illness and death, these women are themselves ill, and have their own emotional responses to impending death. According to Hedge

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(1990), Fleishman (1990) found that among HIV positive people, depression was more prevalent "in females, those unemployed and increasing with the severity of physical symptoms" (in Hedge, 1990, p.381). While some psychological changes may be attributable to AIDS encephalopathy (Zuckerman, et al., 1991), certainly there are additional psychological responses in symptomatic HIV infected individuals which may be ascribed to emotional reactions toward dying.

A great many authors have written about the process of dying. Perhaps most notable among them is Elisabeth Kubler-Ross, who, with her volume, On Death and Dying (1963), opened up a previously unexamined, indeed taboo, territory. Kubler-Ross's well known five stages of dying -- Denial, Anger, Bargaining, Depression and Acceptance -- have not, however, held up under the, now quite impressive, weight of more recent studies. Although authors recognize that many of the stages of dying which Kubler-Ross described do commonly occur, it is generally agreed that these stages come and go, sometimes come again, and sometimes never come at all. Moreover, they are usually interspersed with other feelings and experiences (DeSpelder & Strickland, 1987; R. Ellis, Personal Communication, June 1991). Life-threatening illness is interpreted differently by different people, thus giving rise to quite distinctive reactions (Viney, 1984).

While, then, the process of dying is encountered uniquely by each individual, some commonalities in experience do seem

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to exist. Dying by illness requires constant adaptation to changing physical and emotional states. And there are certain feelings to which the process quite regularly gives rise. Anxiety, loneliness, fear, sadness, anger, helplessness, vulnerability, and guilt are among the emotions reported most frequently (DeSpelder & Strickland, 1987; Rando, 1984; Sourkes, 1982; Viney, 1984). Denial may occur periodically throughout an illness, sometimes marking the transitions to new phases of disease, particularly phases accompanied by additional and unwelcome losses of strength or mobility (DeSpelder & Strickland, 1987; R. Ellis, Personal Communication, June 1991; Rando, 1984; Sourkes, 1982). Many authors cite fears of loss of control over identity, relationships and bodily functions (DeSpelder & Strickland, 1987; Rando, 1984; Sourkes, 1982; Viney, 1984). A dying person commonly fears being defined by illness, dreads losing control over physical and mental boundaries, and feels great apprehension at the prospect of isolation and abandonment. Certainly, among HIV infected individuals, the likelihood of actually being in a state of isolation, without either friends, family or sympathetic medical personnel, is far greater than it is for those with other life-threatening diseases (Britton & Zarski, 1989; Kubler-Ross, 1987). Although many people who suffer from a life-threatening illness experience the effects of the social stigma associated with disease; few, if any, do more-so than those who are infected

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with the virus that causes AIDS (Britton & Zarski, 1989; Kubler-Ross 1987).

Denial of disease is particularly common during periods of temporary abatement of symptoms during an illness. Given the sometimes lengthy asymptomatic incubation period of HIV, it is not surprising that many asymptomatic HIV infected individuals are able to deny the potential severity of their condition to the extent that they may not seem troubled by it. Catalan and Riccio (1990) report that most studies do not seem to indicate that asymptomatic HIV infected individuals suffer greater psychological distress than do seronegative controls. However, an asymptomatic HIV infected mother who has an infected child in need of medical attention and sometimes treatment is in quite a different position. Such a mother is faced, on a daily basis, by a child who may well serve as a reminder of that mother's own illness and impending death. How such a mother might use denial to cope with concerns and fears about her own, as well as her child's health status, remains to be seen. Perhaps the presence of an infected child makes it more difficult to deny the true situation, forcing an HIV infected mother, though she may be asymptomatic, to confront the bleak and terrifying reality of her condition. Perhaps, such a child illustrates too vividly just what may happen as health deteriorates and thereby compounds the emotional intensity of the situation for an HIV infected mother, contributing to more pronounced, insistent and

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complete denial.

Being ill herself, and with the same disease of which her child is dying, the HIV infected woman is unlikely to come to the calm acceptance of her child's death which is described above. For a seropositive woman, such reconciliation would necessitate a simultaneous acceptance of her own impending death. Indeed, the handling of the actual death of her child is just one example of how intertwined her own illness experience must become in her responses to her ill child. In caring for her dying child, the dying mother confronts her own mortality in an entirely different way than does the healthy mother who faces the loss of a child.

The experience of being ill and simultaneously having awareness of another's death is clearly associated with much anxiety. Sourkes (1982) notes that the greater the identification with the one who is dying, the greater is the fear and sadness which ensues. Hence when Reidy, et al. (1991) above noted the painful implications of having multiple family members infected with HIV, they only just began to touch on the implications for a woman who has transmitted the virus to her child.

Natterson and Knudson (1960) refer to the death of the child as the "symbolic death" of the mother. They describe how a mother feels a sense of her own mortality in the face of her child's illness. Edelstein (1984) notes that a mother often sees her child as a "part of herself" and therefore,

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"Any confrontation with death means not only the loss of a loved one but an assault on her sense of immortality." She continues, "Given that the child is the major link to the future, it may be all the more devastating" (p.33). Rando (1984) too writes of the death of a child as foreshadowing the parents' own death, thus prompting concerns about "their own vulnerability and mortality as they struggle to cope with that of their child" (p.401).

For an HIV infected woman, a child who is likewise infected and ill is more than symbolic of her plight. Meyers and Weitzman (1991) write of an HIV infected mother, "A mother may see her own fate reflected in the rapidly progressive disease of the child" (p.177). They go on to state that this may have, "dramatic implications for her sense of responsibility for her child's condition and her sense of and will to face her own disease and its treatment" (p.177). For an HIV infected woman, the significance of first bearing and then losing her infected child must be multi-faceted. A mother who has transmitted HIV to her child may come, through her child's demise, to view her own health status more pessimistically. She may see herself as having an inability to produce anything healthy and thereby believe that her body has been entirely affected by the disease. This view would likely contrast with the experience of the mother who is herself HIV infected but bears at least one healthy child. This mother may feel that her capacity to carry a child inside

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of her, unscathed by illness, is indicative of the limited progression of her disease. Not only, though, might HIV infected mothers view their own illnesses differently depending on whether they have transmitted the virus to their children, but more abstractly, the children who have not been infected may offer their mothers an opportunity for symbolic immortality to which the mothers of infected children do not have access.

According to Robert Jay Lifton (1977), humans have a compelling need to relate to the time beyond their individual life span. Lifton characterizes this urge as the need for "symbolic immortality" and describes five ways in which this sense of immortality may be expressed. The first is the "biologic" mode by which Lifton refers to the sense of living on through and in one's offspring. The second mode is the theological idea of the transcendence of death through spiritual attainment. The third of Lifton's modes of symbolic immortality is "works." By this he refers to the sense that one's contributions to the world, be they in the form of writing, teaching, influence or other creative acts, will not die. The fourth way of achieving a sense of symbolic immortality is accomplished through "being survived by nature itself," what Lifton calls attaining a sense of "eternal nature" (Lifton, 1977, p.279). The fifth and final mode depends entirely on a state of mind; this is the state of "experiential transcendence." A purely psychic state in which

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time and sense of mortality cease to exist, Lifton writes of experiential transcendence, "Poetically and religiously this has been described as 'losing oneself.' It can occur not only in religious or secular mysticism but also in song, dance, battle, sexual love, childbirth, athletic effort, mechanical flight, or in contemplating works of artistic or intellectual creation" (Lifton, 1977, p. 279). Lifton argues that in this age of nuclear weaponry, environmental destruction and rapid social and political change, the imagery of extinction and dislocation, "leave us in doubt about whether we will 'live on' in our children and their children, in our groups and organizations, in our works, in our spirituality, or even in nature..." (Lifton, 1977, p.280). He believes that the loss of faith in these modes of achieving symbolic immortality leads people to plunge into the mode of experiential transcendence: the mode that Lifton believes has been "discovered anew."

Certainly, despite cultural and historical trends, the expression of the search for symbolic immortality may take on different forms in different groups of individuals. How, then, might HIV infected women seek symbolic immortality? These women are, predominantly, urban dwellers, isolated from family, friends and community, often untethered to a cultural or social network, weighed down by concerns for basic necessities. Some might explore the mode of experiential transcendence, although it seems likely that most may feel too

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bound to daily and pressing concerns, to moment by moment questions of comfort, care and security for themselves and their children to "lose" themselves. It seems doubtful that many such women have the peace of mind required for the accomplishment of a sense of their own personal transcendence. Though likely a comfort for some, the knowledge that nature itself will survive them may not bring a sense of symbolic immortality to many HIV infected women. Certainly many of these women seek symbolic immortality through spirituality or religious beliefs; but many others have become alienated from religious institutions due to their unconventional lifestyles. And while some have, doubtless, contributed to the world in ways that they feel will live on, for a good many HIV infected women it seems likely that sexual reproduction is an important mode of achieving symbolic immortality. Besides being a highly accessible mode, it is also one which may seem compelling to one who's life is prematurely threatened by disease. Surely a child is the most concrete, the most visible, the clearest indication that one has lived. As Lifton notes, the biological mode of symbolic immortality is the most "obvious." This avenue is, moreover, consistent with cultural expectations in many Black and Hispanic communities. Janet Mitchell, a perinatologist at Harlem Hospital, has indicated that babies and pregnancy have a special symbolism for many poor women of color (Levine & Dubler, 1990). Mitchell comments on the great value that Latino and Black

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cultures place on a woman's fertility (Levine & Dubler, 1990). These women, living with a life-threatening illness and a need to have a sense of symbolic immortality, in a culture that promotes prolific childbearing may become particularly invested in producing a well child.

Several studies from different parts of the world have indicated that knowledge of positive serostatus does not affect decisions regarding termination of pregnancy (Barbacci, 1990; Irion, 1990; Stratton, et al., 1990; Sunderland, 1989 - all as cited in Sherr, 1990, p.404-5; Selwyn, et al., 1989). In a later study Sunderland, Minkoff, Handte, Moroso and Landesman (1992) concluded that knowledge of HIV seropositivity was associated with decisions to terminate pregnancies, however, such knowledge did not influence the rate of future conception. Indeed, Sherr (1990) reported an increase in the pregnancy rate among HIV infected women as compared with their seronegative controls. Women who are infected with the HIV virus, despite the possibility of virus transmission to their children, become pregnant just as often as seronegative women, and according to some research, choose to terminate these pregnancies at a rate no higher than that of uninfected women. And this is despite what must, in many instances, be considerable anxiety as to the future prospects of any children born uninfected - those who must be expected to outlive their mothers.

Many HIV infected women who have borne an infected child

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go on to have additional children despite counseling discouraging them from reproduction (U.S. Department of Health and Human Services, 1987). In attempting to interpret these findings, the U.S. Department of Health and Human Services' Report of the Surgeon General (1987) suggests that, "Childbirth may provide self-esteem or be culturally expected." As well as providing self-esteem, being culturally expected, and providing a sense of symbolic immortality, bearing a healthy child may have, for an HIV infected woman, additional implications. An infected woman may feel that she is less affected by disease if she is able to bear a healthy child.

For an HIV infected woman, the emotional implications of bearing an infected child are likely quite different from those of bearing an uninfected child. There is not, to date, any scientific evidence indicating that an infected woman who bears an uninfected child has herself a better prognosis than her infected counterpart who bears an infected child. Nevertheless, it is easy to imagine that a woman who transmits her disease to her child may have a profoundly different experience both of that child and of herself than a similarly infected woman whose disease is not transmitted to her child. Some of the areas in which such differences may emerge have been suggested above, but these, while intuitively reasonable, have not been examined by controlled studies of the population in question. The goal of this work is to begin to explore,

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in a systematic manner, some of the ways in which the serostatus of the child of an HIV infected woman impacts on that woman. Specifically, this study will explore: the impact of offspring HIV diagnosis on maternal defense mechanisms and affect maturity -- particularly around themes of future, motherhood, and separation; the impact of offspring HIV diagnosis on maternal impressions of and identifications with children; and the impact of offspring HIV diagnosis on HIV infected mothers' perceptions of their own disease processes and body integrity.

Considering the sometime use of denial by mothers of children with cancer, and given the often agonizing losses and bitter struggles of daily life borne by HIV infected mothers of HIV infected children, it seems reasonable to speculate that such HIV infected women would rely heavily on denial in attempting to cope with their life situation. HIV infected mothers of uninfected children, while suffering many of the same hardships as those women who have transmitted the illness to their children, do at least have the knowledge that they have created a child who will survive them into the future. While it may be that the mothers of HIV infected children use the psychological defense of denial more readily in all situations that touch on issues relevant to themselves or their children than do the mothers of uninfected children, this difference, if it exists, may, perhaps, be revealed most glaringly in the anticipation of the future by these women.

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In at least one significant respect, anticipation of the future for these two groups of women is likely to be dissimilar. For the mothers of children uninfected by HIV the prospect of the future may seem bittersweet; though it holds the not so distant prospect of the loss of their own lives, there may be some comfort in the promise of their offspring's enduring presence. These women may well feel that they will live on symbolically. Though they themselves will suffer a life shortened by AIDS, they may feel that they have not lived in vain; they have created. For the mothers of HIV infected children, however, the future may be marked by a series of losses with little, if anything, to leave behind. I hypothesize that HIV infected mothers of HIV infected children utilize more extreme, that is, reality distorting defense mechanisms, and exhibit an overall lower level of affect maturity particularly in handling themes of motherhood, separation and the future than do their HIV infected counterparts who have not transmitted the virus to their children.

Given the experience of having a life-threatening illness in common with their children, mothers who are infected by HIV and have transmitted the virus to their children are expected to express either extreme over-identification with their children, or to be highly defended against such identification and express little in the way of felt similarities with their children. Mothers who are infected with HIV and have both

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uninfected and infected children are expected to distinguish between them along these lines. As noted above, the tendency for a mother to identify with her ill child is strong; however, the fact that often the HIV positive child's health status will deteriorate before the mother's may mean that the mother's experience of her child is as a harbinger of her own worsening condition and demise. Feeling identified with, or even strongly connected to, and empathic toward such a child may feel too dangerous to the similarly infected mother. Her own death anxiety may prevent her from forming a close and strong identification with her child. Such a mother may also ascribe less overall positive meaning to these children; the children may themselves seem an embodiment of the disease and/or potent signs of their mothers' failure.

Whereas the mothers of uninfected children may see those children as an accomplishment on their part, proof that the illness is not all encompassing, the mothers who have transmitted HIV to their children cannot feel thus comforted. The children, for these women, may, in some sense, seem proof of the thoroughness with which the disease has affected their bodies. Hence, the women who have transmitted HIV to their children are expected to have a more negative subjective sense of their own bodies and represent the disease as more enveloping than are their counter-parts who have borne uninfected children. The women who have borne both infected as well as uninfected children may perceive their bodies and

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disease process less negatively than those women who have exclusively HIV infected offspring although this is likely highly dependent on a number of variables such as the serostatus of their youngest child, and their own symptomatology.

As the AIDS epidemic escalates among inner-city intravenous drug users, their sexual partners and children, the need for medical, social and psychological knowledge and services all escalate accordingly. Comprehension of the psychodynamics at play in the interaction of HIV infection and motherhood is essential to providing well-informed psychological assistance to affected women and their families. Despite the critical need for elucidation of the intricate psychological experience of HIV infected women with children; despite the critical need for knowledge about the ways in which psychological interventions might prove helpful to these women and their children, little research to date has focused on these issues. This work will attempt to illuminate some aspects of the psychological experience of HIV infected mothers with the hope that through such efforts, some of the needs of these women and their families as well as strategies to meet such needs may be identified.

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Methods and Measures

Sample

Four groups of mothers comprised the sample for this study. The first group consisted of 10 HIV infected mothers of HIV infected children (II). The second group consisted of the same number of HIV infected mothers of uninfected children (IU). In the third group, also of 10, HIV infected mothers of at least one uninfected and one infected child were included (IIU). The final group, a "control" group consisted of 10 physically healthy mothers of physically healthy children (UU). The mothers in this final group were matched as closely as possible with the HIV infected women for such variables as socio-economic status, living conditions, family composition, employment status, race, ethnic origins, age and history of intravenous drug use. The ages of the children were variable, ranging from several months to approximately ten years. Among the mothers with the youngest children, inclusion in the study sample was contingent on the children's definitive diagnosis. To the extent possible, participants in the three groups were matched for severity of illness, hospitalization history and, among those with infected children, symptomatology and hospitalization histories of the children.

Recruitment

Over the course of 13 months (from September 1992 through

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October 1993) 67 women were approached by the author at the Pediatric Infectious Disease Clinic at Bellevue Hospital and their participation in this study requested. Of these women, 63 agreed to participate and 47 actually did so. The reasons for non- participation of the 16 women who initially consented to take part in the project varied widely from a change of mind to logistical and physical obstacles. Of the 16, one would have been in the II group of women, 5 in the group of IU women, 4 in the IIU group of women, and 6 in the UU group of women. Four women who were approached refused to participate. One of these women would have been from each of the four groups. One protocol was not completed due to the participant's decision to obtain care for her children at a different hospital. Six protocols were eliminated after they had been completed. Of these, one was that of a woman who was discovered to have a child living in Puerto Rico and dying of AIDS at the time of our meeting, a potentially serious confounder. The second was that of a participant who reported during our interview that she was not living with her youngest child, about whom many of the questions revolved. Two protocols were eliminated because no information was available regarding the participants' health status. The fifth protocol was eliminated due to significant psychopathology of the participant which became evident during the interview. Finally, the sixth protocol was eliminated when the child of that participant, thought to be infected, seroreverted. This

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made it clear that the child had not been definitively diagnosed at the time of the interview and therefore the participant did not meet one of the criteria for inclusion in this study. After all exclusions, 40 women remained: 10 in each of the 4 groups.

Participant Demographics

Of the 40 participants, 19 were Black, 17 Hispanic (16 of the Hispanic women specified that they were Puerto Rican and 1 Equadoran), and 4 White. Their ages ranged from 20 to 47 with a mean age of 30.7 (SD = 6.2). Fourteen women were single, eight were married, six were living with men, five were separated, four were divorced and three were widowed. Approximately half of the 40 women were living alone with their children and half with at least one other adult. Fourteen of the women disclosed no history of drug use while 26 did report past use of drugs. One woman acknowledged her current use of cocaine recreationally. Six of the women were employed at the time of their interview; the remainder were receiving public assistance. The mean number of years of schooling for the group was 12.1 (SD = 1.6).

Of the 30 infected women, 23 reported sexual acquisition of HIV, 4 attributed transmission to intravenous drug use; 2 did not know how they had acquired HIV; and 1 participant declined to answer. The mean time since diagnosis of HIV infection among the infected women was 3 years (SD = 1.7

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years) with a range of 4 months to 6 years. Thirteen of the infected women were symptomatic and 17 were asymptomatic at the time of the interview (according to CDC criteria).

The 59 children included in the study ranged in age from 6 months to 9 years for the infected children (*M* = 3.1 years, SD = 2.7 years) and 2 months to 23 years for the uninfected children (*M* = 5.7, SD = 5.8). Of the 20 infected children, half were boys and half girls; of the uninfected children, there were 23 boys and 16 girls. The mean time since diagnosis of HIV infection among the infected children was 22.5 months with a range of 4 months to 4.5 years. Finally, among the HIV infected children 12 were symptomatic (according to CDC criteria) and 8 were asymptomatic at the time of the interview. (See Appendix A: Center for Disease Control criteria for classification of HIV/AIDS in adult and pediatric populations and Appendix B: Table of demographics for each participant)

Procedures

Each mother was approached during a regularly scheduled visit to the Pediatric Infectious Disease Clinic at Bellevue Hospital Center. At this time the study was described, any questions about it answered, and, if the mother agreed to participate, a consent form was signed (See Appendix C). For mothers who chose to participate, a meeting was planned either for her child's next regularly scheduled clinic visit or for

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another mutually convenient time. Each mother was assured that her decision as to participation would in no way affect the care that either she or her child received at Bellevue Hospital.

At the time of a decision to participate in the study, each mother and each of her children were assigned a random number for purposes of identification. The name-number participant list was kept in a locked cabinet at Bellevue Hospital. All materials, including texts of TAT stories, questionnaires, and interview data were identified exclusively by participant number. Consent for access to medical histories as well as permission to communicate with each woman's primary care physician were also requested at the time of the initial contact. Any medical information obtained was immediately coded to ensure total confidentiality.

After the initial contact was made, and the informed consent signed, each participant attended a meeting with the author. Appointments with participants lasted for approximately two hours. All sections of the meeting were completed with all participants whose protocols were included in data analysis. In four instances a second meeting with the participant was necessary in order to complete all tasks. During the interview, participant's children who were old enough to do so played in a playroom located on the same floor as the clinic; those who were too young for this were attended by those child-life workers who regularly assisted during

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clinic hours. Each participant was reimbursed ten dollars to cover any expenses associated with the visit.

The protocol followed with each participant consisted of the following:

- Nine cards from the Thematic Apperception Test (Murray, 1943) were shown and stories from the mothers requested.

- Several semantic differential tests (Osgood, Suci, & Tannenbaum, 1957) were presented. The mothers were asked to respond by indicating where the concepts "ME," "THE FUTURE," " MY BODY," "MY CHILD," and "SICKNESS" fell with respect to a variety of bipolar opposite adjectives (See Appendix D).

- Each mother was asked to complete a drawing task regarding her subjective sense of her own health status/disease process (See Appendix D).

- A semi-structured interview concluded the meeting. Topics discussed included: participant response to the drawing task, religious beliefs, experience of mothering, future reproductive intentions, sexual practices, life stresses recently experienced, drug use history, as well as basic demographic information (See Appendix D).

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To further ensure both confidentiality and reliability of the scoring process, though the interviewer (the present author) was aware of the group of which each participant was a member, an independent scorer knew the women only by participant number. Each TAT story was recorded and transcribed. The stories were arranged by card in random order i.e., they were not arranged by participant. Each element of the protocol was handled similarly.

Measures

The Thematic Apperception Test, commonly referred to as the TAT, consists of the presentation of a series of pictures and the request that the subject tell stories in response. Stories collected in this way often reveal much information about a subject's motivations, emotions, wishes and conflicts. The fact that the stories provide such a rich source of information is largely due to the tendency of people to "interpret an ambiguous human situation in conformity with their past experiences and present wants..." (Murray, 1943). Moreover, because participants are not speaking directly about their thoughts and feelings, the task is a relatively unthreatening one.

The TAT was scored in two ways. The first, based on a method developed by Cramer (1991), evaluated the defense mechanisms utilized by participants. Cramer's method entails the scoring of each story for occurrences of denial,

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projection and identification. The term "defense mechanism" is used by Cramer (1987) to refer to "any cognitive operation that functions so as to protect the individual from the disruptive effects of excessive anxiety" (p.598). Defenses thus defined are adaptive, though when used in excess they may distort reality. Cramer (1987, p.598) suggests, along with many others, that defenses may be considered as hierarchical; some are more "primitive" or "immature" and others more "mature" or complex. Cramer (1987) considered the developmental course of denial, projection and identification and found that denial, the most "primitive" of the three was used most by the youngest group in her sample. Projection, hypothesized to be "more mature than denial but less mature than identification" (p. 608) predominated in the middle age groups. Identification, the most "mature" of the three defenses was employed most by the oldest children in Cramer's sample. Thus, Cramer's study is consistent with, and, indeed, lends empirical support to theories which regard defenses as developmentally hierarchical.

Cramer and Gaul (1988) further argued that under conditions of stress the use of defenses would shift in their developmental level. These authors examined the effect of stress on children's use of defenses via failure experiences and found that under conditions of failure, children's characteristic defense mechanisms did regress. Adults too have been shown to use "lower" level defenses under conditions

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of extreme stress (Hackett, Cassem & Wishnie, 1968).

Thus, the present author predicted that the characteristic defenses utilized by HIV infected women who had transmitted the virus to their children would differ from the defenses of those women who had not transmitted HIV to their children. I anticipated that the women whose children were infected with HIV, would utilize "lower" level defenses in an attempt to combat, to cope with the extreme anxiety and upset induced by the combination of their own and their children's disease. The mothers having both infected and uninfected children were expected to fall somewhere between the above two groups in their use of defense mechanisms. The results from this group were presumed to depend, perhaps to an even greater degree than the other groups, on a complex interaction of variables. Some of the variables which were expected to come into play for this group were the women's own and their children's symptomatology, external stresses and supports, and the health status of the most recently born child. Women in the uninfected control group were expected to utilize "higher" level defenses than any of the other groups.

Cramer's method is a practical one in that the levels of "development" are clearly defined and scorable. For each defense, Cramer specifies seven scoring categories each of which represents a different element of that defense. The categories for scoring denial are as follows (Cramer, 1991):

(1) Omission of major characters or objects
(2) Misperception

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(3) Reversal
(4) Negation
(5) Denial of reality
(6) Overly maximizing the positive or minimizing the negative (7) Unexpected goodness, optimism, positiveness, gentleness.

Explicit scoring criteria for Cramer's method are detailed in a scoring manual with numerous examples (Cramer, 1991). Scores are summed across stories to determine an overall score for each defense. Additionally, scores in this study were determined for the past, present and future component of each story.

In a study of the use of denial, projection and identification in a group of hospitalized patients, Cramer, Blatt and Ford (1988) used Cramer's scoring method with inter-rater correlations of r = .80 for denial; r = .78 for projection; and r = .59 for identification. A prior study by Cramer (1987) utilizing the same scoring method demonstrated inter-rater reliabilities of r = .81 for Denial, and r = .71 for Projection and Identification.

The second method by which the TAT was scored, developed by Thompson (1981), evaluates stories for the "maturity of affect" they reflect. Affect maturity is a concept utilized by Thompson in determining how feelings are experienced and handled. Thompson conceptualizes affect maturity as evolving along a developmental continuum, but notes that regressions and fixations can occur. She does not state the circumstances related to the regression of affective response, but it seems

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reasonable, given the research noted above with reference to stress and defenses, to assume that characteristic affect maturity may be modified by experiences of stress or conflict. Thus, themes of motherhood and separation might prompt, in HIV infected women with similarly infected children, a regression in affect maturity if such themes are, as is hypothesized, conflictual for these women. Women in this group (II) were expected to exhibit a lower level of affect maturity, particularly on cards eliciting such themes, than would women in the IU group. The IIU group's scores were expected to be variable, depending on such factors as the health of both offspring and mother at the time of the testing. The UU group of women was hypothesized to exhibit the highest level of affect maturity. Thompson's scale for "scoring" affective responses takes into consideration such elements as the extent to which an affect is represented as global, eventlike, irreversible, and undifferentiated from its object, from the self, and from its expression. Thus, according to Thompson, the more differentiated is affect, the greater is the capacity for experiencing mixed and contradictory feelings toward the same object.

The development of the Affect Maturity scale involved the use of a method adapted by Thompson from Loevinger, Wessler, & Redmore (1970, as cited in Thompson, 1986). Thompson notes that the process required "complex input from clinical judges" (Thompson, 1986, p. 213), and shows that interjudge

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reliability is acceptable. In data generated by Thompson's 1986 study, judges agreed within one scale point 89.3% of the time for individual item ratings, and 93.3% of the time for total protocol ratings. Stories are each rated, and then a mean calculated across stories for each subject. This mean constitutes an Affect Maturity Index (AMI) which, along with the associated standard deviation, summarizes the scores of each subject. Subjects were shown to respond consistently across items to a significant degree, lending support to the notion of characteristic affect maturity.

Importantly, especially given the high percentage of bilingual mothers included in the current study, affect maturity, as measured by Thompson's method, was not contingent on either verbal ability or fluency (there were no statistically significant correlations found between affect maturity indices and either length of stories or verbal ability as measured by the WAIS vocabulary subscale).

TAT cards 3BM, 4, 6BM, 13MF and 15 have been shown by Murstein (1972) to elicit affect laden stories, however for the specific interests of this study, cards 2, 3BM, 3GF, 7GF, 8GF, 6BM, 8BM, 13B, and 13G (Farm scene, figure slumped with gun, woman clutching door, woman and girl with doll, woman contemplating, man "informing" older woman, surgery with boy looking out, boy alone in doorway, figure going up stairway) were selected in order to maximize the elicitation of themes of parent/child interactions as well as of separation.

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Defenses and affect levels were scored for each story. The totals for defense and affect level for each group were determined and compared with the totals found for the other groups i.e., across all stories. The scores were also compared story by story or card by card in order to determine whether particular themes impacted differently on the groups. Finally, the distribution of defenses within stories was examined. Each story was broken down based on its past, present and future component and analyzed to determine whether anticipation of future impacted differently on the defense use of these groups of women.

The present author and an independent scorer attained an acceptable level of inter-rater reliability on TAT stories unrelated to this study before the data obtained for this research was scored (by the independent scorer). Inter-rater reliability was reestablished after 50% of the stories had been scored.

Following the TAT, several semantic differential tests were administered. Semantic differentials are quite flexible in their applications and have, in fact, been employed in the exploration of a variety of areas such as: self perception (Minor, Karr & Davis, 1984); attitudes and perceptions of time (Sanders, 1986; Skrzynski, 1981); depression (Karoly & Ruehlman, 1983); and identification patterns among children of Holocaust survivors (Felsen & Erlich, 1990). A semantic differential test consists of a concept, for example "The

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Future," and a list of pairs of bipolar adjectives, for example, "good-bad," forming a scale along which participants rate the concept. There are generally seven points forming a continuum between the two adjectives and participants must decide whether the concept is "very closely related" to one adjective, "quite closely related," "only slightly related" or whether the concept is either equally related to both of the adjectives or unrelated to both (taking the middle position on the scale). Thus, scale positions are marked 1 - 7 or -3 - +3. By marking the relatedness of a concept to a variety of descriptors, the "semantic space" in which the concept lies for the participant may be determined. There are numerous, indeed infinite, dimensions of semantic space, but those used most commonly are the evaluative, potency, and activity dimensions. Using factor analysis to evaluate 50 scales, Osgood, Suci and Tannenbaum (1957) recognized these three dimensions or factors as the ones into which most bipolar scales were inclined to fall. Half of the scales used in that analysis fell into the factor known as Evaluative (including such scales as good-bad, clean-dirty and happy-sad). Nine scales fell into the factor of Potency (including weak-strong, large-small, and heavy-light). And six scales, including fast-slow and active-passive, fell into the factor of Activity. The remaining scales emerged without clear groupings into any factors. Despite persistent attempts at identification of additional factors, Osgood, et al.'s

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original three have remained primary. Thus, although researchers may devise their own factors, relevant to the research at hand, the three noted above are useful in that they have been utilized frequently and are clearly associated with certain adjective scales. Though the dimension of potency was represented by the scales used in the present study, the evaluative dimension was drawn upon most. Recent studies have shown that the evaluative factor is the most consistent when used in varying kinds of research (Emmerson & Neely, 1988). Although some adjective pairs not contained in Osgood, et al.'s original lists were included in this project, these were used only for comparisons which did not imply that they were representative of factors. Only those scales clearly associated with a factor (Evaluative, Potency or Activity) as previously determined by factor analysis, were utilized in any statistical analyses of the data dependent on parcelling into factors. By employing the adjectives originally included in Osgood, et al.'s factor analysis it was possible to know with confidence which factors were represented by each adjective pair. Moreover, the reliability and validity of Osgood, et al.'s original factors and scales have long been established. Osgood, et al. report test-retest reliability coefficients with a mean of $r = .91$. As well, the semantic differential as an attitude index correlates significantly with the Thurstone scale as well as with the Guttman scale, with which it has a correlation of rho

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= .78, $p<.01$ (Osgood, et al., 1957). More recent studies have similarly shown the acceptability of the semantic differential method's test-retest reliability as well as its nomological validity (Emmerson & Neely, 1988; Ohanian, 1989; Piotrowski, 1983).

Semantic differential tests are often used in the assessment of the "meaning" of a concept. This entails locating a concept with reference to various semantic dimensions, namely: evaluative, potency and activity. The evaluative factor of the semantic differential may be used by itself as an index of attitude (i.e., favorable/unfavorable). There are numerous alternatives for the analysis of data obtained from the semantic differential. Concepts may be compared with one another within groups -- either broken down by factor, or by individual scales; different groups may be compared in their evaluation of the meaning of the same concept; different groups' attitudes toward the same concept may be compared -- either by comparing the groups' mean evaluative scores, or, by comparisons of individual scales; and a concept's meaning for a particular group may be analyzed either by factor or by an examination of specific scales. In comparing how one concept is assessed by different groups the scores for that concept -- in this study, "MY CHILD," for example -- are summed (broken down by factor) within groups and the means determined. An analysis of variance is then applied, with subsequent follow-up tests if necessary.

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Additionally, specific scales of a concept -- for example, Weak-Strong -- may be statistically compared between groups, again using an analysis of variance.

The data generated from the semantic differentials were analyzed in several ways, addressing more than one hypothesis. In order to examine the extent of similarity (as expressed by participants) between the participants and their children, the meanings attributed to the concepts "ME" and "MY CHILD" were analyzed; the groups were then compared. This provided information regarding the degree of identification of mothers with their children. The inferring of identification through the similarity of semantic differential profiles (i.e., the comparing of the rating of two concepts one of which is "ME") was introduced by Mowrer (1953) who noted the shifts in parental identifications among patients in therapy with him as their work proceeded. Mowrer observed the strong association between his clinical observations and the semantic measurements periodically administered to patients. A similar concept was also used by Lazowick (1955) who looked at the parents with whom "neurotic" and "normal" children identified. In the present study, the concepts, "ME" and "MY CHILD," were also compared on a number of specific adjective scales.

As a means of addressing the degree of positive versus negative meaning attributed to the children of women in this study, results from the evaluative dimension of the semantic differential "MY CHILD" were considered for each group of

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women.

Women in the II group were expected to be either overly identified with their children or to resist identification, and present profiles for themselves and their children which were quite different from one another. Women in this group were also expected to rate their offspring most negatively on the evaluative dimension. Participants in the IU group were predicted to show much identification with and attribution of positive meaning toward their children, but not to such extremes as might the women in the first group. Women in the IIU group were expected to show a great deal of similarity with one or the other of the children --i.e., either with the uninfected or the infected, but not with both -- and to attribute negative vs. positive meaning to their children depending on their serostatus. Women in the UU group were expected to occupy a middle ground. For women in the UU group, identification with their children and recognition of difference from their children were not expected to be as conflict ridden as for the HIV positive women. Thus, women in the UU group were predicted to reveal more flexibility individually and more variety as a group in their handling of similarity, difference, positive and negative meaning.

Groups were also compared as to their attitudes toward "THE FUTURE." While none of the HIV infected women were predicted to have particularly positive attitudes toward the future, women in the II group were considered likely to reveal

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the most negative evaluations of this concept. Participants in the IIU group were also expected to express somewhat pessimistic attitudes; as stated above, however, prediction for this group was quite complicated, depending on a variety of variables. Though the group of IU women were, among the HIV infected women, expected to be the least negative in their expectations for the future, negative assessments of the future were not considered unlikely. The UU group was predicted to rate the future most positively of all the groups.

The information afforded by the semantic differentials was used, as well, in evaluating mothers' subjective perceptions of their own health, sickness, and physical well being. The groups of women were compared as to their attitudes toward their bodies as reflected in the "MY BODY" semantic differential, and the potency attributed to the concept of "SICKNESS." The different groups were also compared along the "healthy-sick" scale included in the semantic differential "ME." Women in the II group were expected to have the most negative assessments of their bodies, attribute the greatest potency to "SICKNESS" and rate themselves as most "sick" on the "Healthy-sick" scale. As above, women in the IIU group were predicted to rate themselves closest to this first group of women in their assessments on the above scales although this was certainly thought to be dependent on multiple variables. Women in the

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IU group were expected to assess their bodies more positively, attribute less potency to "SICKNESS," and regard themselves as less sick on the "Healthy-sick scale" than the two aforementioned groups. The group of UU women were expected to regard their bodies most positively, attribute the least potency to "SICKNESS" and regard themselves as the most healthy on the "Healthy-sick" scale.

In order to address the hypothesis that women in the II group perceive their bodies as having been more affected by disease than do women in the IU group, a drawing task was used in addition to the semantic differential "SICKNESS," the "Healthy-Sick" scale of the concept "ME," and the concept "MY BODY." The perceived extent, location and severity of disease was explored through this task. Participants were presented with two outlines of human (female) figures -- a front, and a back view. They were asked to color in the areas they considered to have been affected by sickness and to indicate by color (red - greatest severity; orange - medium severity; yellow - least severity) which areas were most seriously affected. The Figure Outline was scored in two ways. In the first method, the number of locations colored was calculated and then multiplied by a value of 1,2 or 3 based on the color used for each location. (Red as the most severe was assigned a value of 3, orange a value of 2 and yellow, a value of 1). A "Location Score" was in this way derived for each drawing; average location scores were then calculated for each group.

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In the second method, the figure was divided up and percentages assigned to each section of the body based on established medical guidelines designating average body surface area. The percentages of the body covered by each of the three colors were calculated for each drawing and an "Area Score" derived (based on the color value multiplied by the percentage of body covered). As with the location scores, average area scores were then calculated for each group.

The two methods were found to be consistent with one another. The area score was found to be somewhat less stable for two reasons. This score relies on an assessment of area which is necessarily subjective given the great variety of drawing styles; and it is also more subject to skew based on one or two very high or very low scores in a group because the potential range for area scores is much larger than the potential range for location scores. The standard deviation was much greater in every group for the area scores than for the location scores. Given the greater stability of the location scores results were reported based on these rather than on the area scores.

In order to establish the extent of similarity between the women's subjective perception of their disease and objective criteria, the women's physicians were presented with these figure outlines as well. Physicians were asked to shade in the areas of the body (for each participant) which had been affected by illness and to indicate by their use of color, as

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the women themselves did, the severity with which different areas had been affected. Comparisons were then made between the physicians' and the women's representations of the extent of illness. The four groups of women were compared as to the extent to which their subjective perceptions of their illness coincided with their physician's representations. It was hypothesized that the II group of women would locate their illnesses in areas associated with reproductive functions to a greater extent than would women in the IU group, and to a greater extent than would their physicians. Women in the II group were also expected to represent their illnesses as more severe and as affecting a greater percentage of their bodies than would women in any of the other groups. Consistent with some of the above hypotheses, results on this measure for women in the IIU group were difficult to predict and dependent on a variety of factors including the birth order of the offspring of these women.

The final part of the meeting with each mother consisted of a semi-structured interview in which such topics as future reproductive intentions, spiritual beliefs, basic knowledge of HIV, recent life stresses, and less structured impressions of the child (such as who the child resembles physically and temperamentally) were explored. Although the emphasis of interviews varied between women, a set of specific questions was addressed in each meeting. Included in the interview were questions specifically addressing sexual practices. This

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series of questions consisted of queries as to frequency of unprotected sexual encounters and attempts at conception and included a discussion of future reproductive intentions and wishes. The interview included questions about personal experience with HIV only after a participant herself made reference to the topic. Interviews were tape recorded and later transcribed. Interview transcripts were closely studied and contributed greatly to the interpretation of all empirical data.

Summary: Hypotheses and Measures

As stated above, the goal of this work was to begin to explore, in a systematic manner, some of the ways in which the serostatus of the child of an HIV infected woman impacts on that woman psychologically. Specifically, this study explored: the impact of offspring HIV serostatus on maternal defense mechanisms and affect maturity -- particularly around themes of future, motherhood, and separation; the impact of offspring HIV serostatus on maternal impressions of and identifications with children; and the impact of offspring HIV diagnosis on HIV infected mothers' perceptions of their own disease processes and sense of their bodies.

- Hypothesis I

  Participants in the II group were predicted to utilize more extreme, that is, reality distorting

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defense mechanisms, particularly in handling themes of motherhood, separation and the future than were participants in the IU group. The defense use exhibited by women in the IIU group was expected to be contingent upon a number of different variables and was not, thus, hypothesized as being more similar to either the II or IU groups. Participants in the UU group were expected to use the least extreme defenses.

The primary measure used in the exploration of this hypothesis was Phebe Cramer's method for scoring defenses on the Thematic Apperception Test. Stories were scored by theme as well as by time component (i.e., past, present and future). In order to further test this hypothesis, several other measures were used in the assessment of denial specifically. Comparisons of the Figure Outline Test as completed by participants and their physicians provided a measure of denial as it relates to assessments of health status; interview questions related to sexual practices and reproductive intentions provided a behavioral criterion for observing denial; and responses to several elements of the Semantic Differential Test also provided insight into the extent of denial utilized by participants.

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- Hypothesis II

  Women in the II group were expected to exhibit a lower level of affect maturity particularly when confronted with themes of separation and motherhood than would women in the IU group. As noted in the above hypothesis, the level of affect maturity exhibited by women in the IIU group was expected to be dependent upon a number of variables; the level relative to the II and IU groups was not predicted. Women in the UU group were expected to exhibit the highest level of affect maturity.

  Anne Thompson's method of scoring Affect Maturity on the Thematic Apperception Test was utilized in testing this hypothesis.

- Hypothesis III

  The II group of women was predicted to express either extreme over-identification with their children, or to be highly defended against such identification and express little in the way of felt similarities with their children. The IU group of women was expected to reveal a sense of being identified with their children but not to the degree anticipated among some of the mothers in the first

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group. Women in the IIU group were expected to distinguish between their children according to serostatus. No specific predictions were made regarding the identification of participants in the UU group with their children.

- Hypothesis IV

Women in the II group were expected to ascribe more negative meaning to their children than would women in the IU group to their children. Partcipants in the IIU group were predicted to distinguish between their children according to serostatus, viewing their infected children more negatively than their uninfected children.

No specific prediction was made for the assessments of the UU group of women of their children.

The Semantic Differential Test was the primary means of researching hypotheses III and IV. The Semantic Differential assessed the degree to which the participants view themselves as similar to or different from their children both in terms of specific qualities as well as a composite of characteristics. Additionally, the Semantic Differential was used to compare mother's evaluations of their different children in order to

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assess positive vs. negative meaning attributed to them. The interview section of the protocol also provided information as to participants' conscious sense of extent of resemblance with their children.

- Hypothesis V

Participants in the II group were expected to have a more negative subjective sense of their own bodies and represent the disease as having affected them to a greater degree than were their counter-parts in the IU group. Women in the II group were, moreover, expected to locate their illness as in the areas of the body associated with reproduction to a greater extent than were women in the IU group. As noted above, multiple variables were expected to impact on women in the IIU group with regard to this hypothesis; thus, specific predictions for women in this group were not suggested.

This hypothesis was researched via the Figure Outline Test and the Semantic Differential. On the Figure Outline Test, body outlines were shaded independently by the participants and their physicians to indicate location and severity of illness. The results of these drawings were compared both between groups and between participants and physicians. Additionally, the

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semantic differentials "MY BODY," "SICKNESS," and "ME" were utilized in comparing the ways in which the different groups of women regarded their own health/illness status.

RESULTS

Demographics

Analyses of variance and Chi-Square tests failed to reveal any significant differences among any of the groups on any of the following demographic variables (See Tables 1a - 1j): age of mother, age of child, mother's education level, time since diagnosis of mother, time since diagnosis of child, race, drug history, employment status, living arrangement, mode of transmission, status of symptomatology (symptomatic vs. asymptomatic) of mother, status of symptomatology of child, and sex of child. A table of demographics listed by participant can be found in Appendix B.

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Table 1a

Table 1a: Mean Values of Demographic Variables by Group*

Group:	II		IU		IIU		UU	
Variable	M	SD	M	SD	M	SD	M	SD
Age	29.20	7.67	30.60	5.30	34.20	5.25	28.60	5.80
Education Level	12.7	1.41	12.20	1.23	11.4	1.59	12.10	1.97
Time Since Diagnosis	3.17	1.79	3.00	1.59	2.41	1.90	N/A	N/A
Age of Children**	2.57	2.62	4.06	2.97	6.69	5.89	4.38	4.94
Time Since Ch. Diagnosis	1.72	1.34	N/A	N/A	1.45	1.21	N/A	N/A

* All values are presented in years
** All children's ages combined (see Table 1b for breakdown by serostatus)

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Table 1b

Table 1b: Mean Ages of Children by Group and Serostatus

Group:	II				IU				IIU				UU			
	01		02*		01		02		01**		02		01		02	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
	2.57	2.62	N/A	N/A	2.64	1.44	6.90	3.32	3.43	3.15	9.95	6.29	2.30	1.31	11.30	6.66

* Women in II group each had only one child
** In IIU group 01 child is seropositive, 02 child is seronegative

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The following legend refers to Chi-square tables below:

Table 1d: History of Drug Use

Y = Past Use of Heroin or Cocaine

Table 1f: Living Arrangement

W = lives with another adult

WO = lives without another adult

Results have been consolidated into these two categories both for relevancy as well as statistical analysis.

Table 1g: Mode of Transmission

S = Sexual

N = Needles (from IV drug injection)

DK = Don't Know

One participant in the IIU group declined to answer this question. In accordance with CDC guidelines, S/N responses are counted as N.

Table 1h & Table 1i: Symp. vs. Asymp.

Symp. = Symptomatic

Asymp.= Asymptomatic

According to CDC criteria (See Appendix A).

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Table 1c:

Race of Participants

Group	W	B	H
II	3	2	5
IU	1	5	4
IIU	0	7	3
UU	0	5	5

X^2 (6, N=40) = 9.331, NS

Table 1d:

History of Drug Use

Group	No	Yes
II	5	5
IU	2	8
IIU	2	8
UU	5	5

X^2 (3, N = 40) = 3.956, NS

Table 1e:

Current Employment

Group	No	Yes
II	9	1
IU	8	2
IIU	10	0
UU	7	3

X^2 (3, N=40) = 3.922, NS

Table 1f:

Living Arrangement

Group	WO	W
II	3	7
IU	6	4
IIU	7	3
UU	5	5

X^2 (3, N=40) = 3.509, NS

Table 1g:

Mode of Transmission

Group	S	N	DK
II	9	1	0
IU	6	2	2
IIU	8	1	0
UU	N/A	N/A	N/A

X^2 (4, N=29) = 4.950, NS

Table 1h:

Asymp. vs. Symp.

Group	A	S
II	7	3
IU	6	4
IIU	4	6
UU	N/A	N/A

X^2 (2, N=30) = 1.900, NS

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Table 1i:

Child Asymp. vs. Symp.

Group	A	S
II	5	5
IU	N/A	N/A
IIU	3	7
UU	N/A	N/A

X^2 (1, N=20) = .833, NS

Table 1j:

Sex of Children

Group	F	M
II	5	5
IU	10	5
IIU	9	11
UU	9	5

X^2= (3, N=59) = 2.210, NS

Results of Psychological Testing

Unless otherwise noted all data were analyzed using one way analyses of variance with a Bonferroni test to assess differences between groups when significant effects were detected. Results are presented below for each of the hypotheses in turn.

1. Denial

Women infected by HIV who had transmitted the virus to their children were hypothesized to rely on denial more heavily than women who had not transmitted the virus to their offspring. This was expected to be particularly obvious when the women were confronted with the themes of motherhood and separation and also in anticipation of the future.

Cramer's (1982) method of scoring defenses on the Thematic Apperception Test (TAT) was the primary means of

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assessing the utilization of denial among the four groups of women. Using this method, the scorer (an advanced clinical psychology graduate student without knowledge of the topic of the research) and the present author achieved an inter-rater reliability rate of .80 prior to the scoring of stories gathered for this project. Reliability was reestablished at the same level after 50% of the stories had been scored.

Women in the UU group (M = 4.4), contrary to expectations, utilized denial the greatest number of times (See Table 2). Women in the II group (M = 4.3) employed denial almost twice as many times as did women in the IU group (M = 2.3)[$F(3,36) = 4.237$, $p<.05$] and nearly 20% more than did women in the IIU group (M = 3.4), although the latter result was not significant.

Table 2: Mean Denial Scores on TAT

Group	Mean	SD
II	4.3*	1.34
IU	2.3	1.34
IIU	3.4	1.35
UU	4.4*	1.90

* = $p<.02$

Among the groups of infected women the II group used the greatest total number of defenses over the nine stories. They also employed denial the greatest proportion of the time that

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a scorable defense was used. This group used denial 40% of the time that they employed a defense, as compared with 37% for the IIU group, 24% for the IU group and 48% for the UU group. UU's proportion of denial use was significantly greater than the proportion used by the IU group [$F(3, 36) = 3.6162$, $p<.05$].

Table 3: Proportion of Denial

Group	Mean	SD
II	.40	.19
IU	.24	.15
IIU	.37	.18
UU	.48*	.16

* = $p<.05$

II women's reliance on denial as a psychological defense was, as noted above, predicted to be most apparent when these women were confronted with themes such as motherhood and separation. Defense scores were compared on a card by card basis in order to assess this hypothesis. While cards 2, 6BM and 7GF did evoke stories containing themes of motherhood and cards 3GF, 6BM and 13B themes of separation more often than did the other cards, no significant differences in defense use were found among any of the groups on any of the cards (See Table 4).

Card 2 elicited 27 stories in which motherhood figured

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prominently. The results noted in Table 4 indicate that denial usage in responses to this card was not particularly high for any of the groups. Responses to Card 6BM included 35 stories in which themes of motherhood predominated; responses to Card 7GF included 37 stories in which such themes were prevalent. Denial scores on Card 6BM for the three groups of infected women were among the lowest for any of the cards. Stories told in response to this card tended, moreover, to be quite straightforward, well organized, and not particularly affect-laden. The IU group of women attained its highest denial score on Card 7GF but this score was not significantly higher than the denial scores of any of the other groups on that card. Nor was that score significantly greater than any of the scores attained by the IU group on any of the other cards.

Cards 3GF, 6BM and 13B elicited the greatest numbers of stories which included a separation or loss. On Card 3GF participants told a number of stories in which themes of separation and loss were central (12), though the majority of stories in response to this card did not involve such themes. Among those stories that did contain these themes, nearly half were told by uninfected women. Responses to this card included a total of only two instances of the use of denial. The dearth of denial use in response to card 6BM has been noted above and with the exception of the group of uninfected women, denial scores on Card 13B were also among the lowest.

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Responses to Card 3BM included the greatest number of instances of denial; however, few of the stories contained themes of either motherhood or of separation. The most affect laden stories and those with most examples of denial were, in fact, told in response to this card. Card 8BM likewise elicited the theme of motherhood not at all, and that of separation only once, but nonetheless evoked many instances of denial. Additionally, the II group of women utilized denial more times in response to Card 8GF than did women in any of the other groups, despite the fact that stories evoked by this card were not generally related to themes of either motherhood or separation.

II women were also expected to use the most denial in confronting the idea of the future. This prediction was assessed in two ways. The first involved a comparison of the use of denial in the three segments of TAT stories: past, present and future. The greatest use of denial across all groups was found in the "present" component of stories. There were a total of 68 instances of denial use across groups and stories -- compared with only 3 instances of denial use in the past, and 3 instances in the future components of the stories. The three examples of denial use in the future component of the stories were evenly divided among the three groups of infected women. Thus, this hypothesis was not supported.

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Table 4: Mean Denial Scores by TAT Card

Group:	II		IU		IIU		UU	
Card	M	SD	M	SD	M	SD	M	SD
2	0.4	0.52	0.3	0.67	0.5	0.53	0.7	0.67
3BM	1.0	0.47	0.6	0.52	1.3	0.82	0.9	0.57
3GF	0.1	0.32	0.0	0.00	0.1	0.32	0.0	0.00
6BM	0.2	0.42	0.1	0.32	0.1	0.32	0.5	0.71
7GF	0.6	0.70	0.7	0.67	0.4	0.52	0.3	0.48
8BM	0.8	0.42	0.2	0.42	0.6	0.52	1.0	1.10
8GF	0.8	1.10	0.1	0.32	0.4	0.84	0.3	0.67
13B	0.1	0.32	0.3	0.67	0.0	0.00	0.6	1.08
13G	0.3	0.48	0.0	0.00	0.0	0.00	0.1	0.32

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This hypothesis was likewise not supported by results from the semantic differential, "THE FUTURE" (See Table 5). The group of UU women obtained the highest (most positive assessment) mean (M = 37.5) on the evaluative dimension of this semantic differential. The lowest score was attained by the group of IU women (M = 27.4); this difference in means was found by an Analysis of Variance to be statistically significant [$F(3, 36) = 3.2329$, $p<.05$]. The difference, however,was not great enough to reach significance upon follow-up with the Bonferroni test.

Table 5: Mean Evaluative Scores on "THE FUTURE" Semantic Differential

Group	Mean	SD
II	31.1	9.33
IU	27.4	11.74
IIU	36.9	6.72
UU	37.5*	4.43

* $p<.05$

Other semantic differentials were also examined in order to assess the employment of denial in the four groups. The Healthy-Sick scale of the semantic differential "ME" was considered as a means of assessing the extent to which women acknowledged illness. Denial here was expected to be evidenced in an unrealistically positive assessment of health

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status. Based on the results of this semantic differential, there were no significant differences found among the infected women of different groups in their ratings of physical well being (II *M* = 4.5, IU *M* = 3.9, IIU *M* = 4.6, UU *M* = 5.2). While results from this scale did indicate that infected women regarded their health status more negatively than did uninfected women, they did not do so to a significant degree. Results from the Healthy-Sick scale of the semantic differential "MY BODY" were consistent with the scores above with no significant differences among any of the groups (II *M* = 4.4, IU *M* = 4.2, IIU *M* = 4.4, UU *M* = 5.7)(See Table 6 for results from both "ME" and "MY BODY" semantic differentials).

Evaluations of the health of offspring based on the Healthy-Sick scale of the semantic differential "MY CHILD" were also considered as a possible source of evidence of denial. Denial, as above, would have been exhibited by unrealistically positive assessments of a child's health. Indications of denial were not apparent based on the results of this semantic differential. Uninfected children received the highest scores from their mothers (IU *M* = 6.5, SD = 1.08; IIU *M* = 6.6, SD = 0.97; UU *M* = 6.6, SD = 0.84). Infected children with uninfected siblings received the lowest scores (IIU *M* = 4.5, SD = 2.32), significantly lower than scores of the uninfected children [$F(3, 36) = 4.33$, $p<.02$] though not significantly lower than the scores of the other infected children (II *M* = 5.2, SD = 1.55).

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Table 6: Mean Scores on Healthy-Sick Scale of "ME" and "MY BODY" Semantic Differentials

Group:	II		IU		IIU		UU	
	M	SD	M	SD	M	SD	M	SD
"ME"	4.5	1.6	3.9	1.79	4.6	1.78	5.2	1.40
"MY BODY"	4.4	1.4	4.2	1.62	4.4	2.27	5.7	1.49

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Scores on both the evaluative dimension and the Weak-Strong scale of the semantic differential "SICKNESS" were analyzed. Women in the II group were predicted to rate sickness both as less powerful and less negative than women in the other groups, thus reflecting greater use of denial. On the evaluative dimension the mean score for women in the II group, though highest (least negative), was not significantly higher than the scores of the other groups (II M = 14.4, SD = 2.88; IU M = 11.5, SD = 4.84; IIU M = 11.7, SD = 4.24; UU M = 12.9, SD = 4.01). Contrary to expectations, women in the II group also attained the highest mean score (Strongest) on the Weak-Strong scale, though this score was not significantly higher than the means of the other groups (II M = 4.0, SD = 1.76; IU M = 3.3, SD = 2.06; IIU M = 2.9, SD = 1.73; UU M = 3.7, SD = 2.16).

Results from the Figure Outline task were considered in two ways as another source of information regarding use of denial by the participants in this study. Instances of physician ratings of effects of disease greater than the corresponding patient ratings were understood as suggestive of denial of illness or symptomatology. The II group of women was expected to show the highest number of such instances; statistical analysis revealed no significant differences among the groups (II M = .33, SD = .50; IU M = .20, SD = .42; IIU M = .25, SD = .46)(UU women's scores were not included in this analysis as they were not regularly seen by physicians).

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The hypothesis that women in the II group would use significantly more denial was also not supported by the finding that all three groups of infected women rated themselves on the Figure Outline task as being more affected by illness than did the group of uninfected women (II M = 11.5, IU M = 14, IIU M = 9.1, UU M = 2.2)(See Table 7). The mean scores of women in the II and IU groups were significantly higher than the mean score of women in the UU group [$F(3, 36) = 5.1417$, $p < .005$]

Table 7: Mean Figure Outline Scores

Group	M	SD
II	11.5*	10.65
IU	14.0*	6.85
IIU	9.1	5.82
UU	2.2	2.49

*$p < .05$

Evidence of denial on a behavioral level among women in the II group was suggested by parts of the interview section of the protocol, though numbers were too small to compute the statistical significance of findings. Women were asked questions regarding sexual activity, use of contraception, and plans for future reproduction. The intention to bear future children among sexually active women in the II group was similar to that expressed by sexually active women in the

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other groups of infected women. II women, however, reported using contraception "sometimes" or "never" (as opposed to "always") twice as often as did infected, sexually active women in the other two groups.

Table 8: Use of Contraception and Reproductive Intentions

	Use of Contraception		Plans for Children	
Group	Always	Sometimes/Never	Yes	No
II	2	8	3	7
IU	6	4	3	7
IIU	5	5	1	9
UU	1	9	7	2

With the exception of total instances of denial -- in which the mean score of women in the II group was significantly greater than that of women in the IU group (as was UU group's mean score also significantly greater) -- none of the findings support the prediction that women in the II group would utilize denial to a significantly greater degree than would women in the other groups.

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2. Affect Maturity

Thompson's (1981) method of scoring the TAT was used to address the levels of affect maturity characteristic of the four groups of women, particularly when confronted with the themes of motherhood and separation. The independent scorer and the present author achieved an inter-rater reliability rate of .80 on this scale prior to the scoring of any participant stories. This level of reliability was reestablished after 50% of the stories had been scored.

Women in the II group were expected to evidence the lowest affect maturity. This hypothesis was not supported as there were no significant differences revealed among the overall mean scores (i.e. across all nine TAT cards) of the four groups. The mean score for all the groups over all the TAT cards was 3.03. The four groups each attained means over all the cards remarkably close to that value (II M = 3.02, SD = .33; IU M = 3.04, SD = .48; IIU M = 3.07, SD = .42; UU M = 3.02, SD = .19) .

As noted above, the lower affect maturity score for II women was hypothesized as most likely evident when confronting themes of motherhood and separation. Thus, individual cards were compared. As noted regarding denial scores on individual cards, although certain cards were more likely to elicit stories containing these themes, a comparison of the mean scores of the four groups on each card revealed no significant differences. An analysis of variance did reveal a significant

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difference between groups IIU and UU on Card 2 (IIU *M* = 2.25, UU *M* = 3.29) [$F(3, 28) = 3.1707$, $p<.05$], however, the difference was not great enough to attain significance upon a follow-up Bonferroni (See Table 9).

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Table 9: Mean Affect Maturity Scores by TAT Card

Group:	II		IU		IIU		UU	
Card	M	SD	M	SD	M	SD	M	SD
2	2.5	0.76	3.0	0.71	2.3	0.89	3.3 *	0.49
3BM	3.1	0.78	2.9	0.33	3.1	0.32	2.9	0.57
3GF	3.1	0.93	2.9	0.57	3.0	0.50	3.0	0.00
6BM	3.6	0.97	3.9	0.93	3.9	0.60	3.1	1.20
7GF	3.4	0.52	3.6	0.73	3.4	0.73	3.3	0.50
8BM	2.9	0.38	2.9	0.38	3.1	0.69	2.8	0.45
8GF	2.9	0.60	2.9	0.64	2.9	0.78	2.8	0.67
13B	2.9	0.32	3.1	0.33	3.0	0.00	3.0	0.50
13G	2.8	0.84	2.2	0.75	3.0	0.82	3.0	0.63

* $p<.05$

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3. Identification with and Assessment of Offspring

Identification with and evaluation of offspring were addressed via the semantic differentials "ME" and "MY CHILD." Women in the II group were hypothesized to over or under-identify with their children and to rate them most negatively. IIU women were expected to rate children according to their serostatus. None of these hypotheses were substantiated by findings.

To evaluate the extent of identification of mothers with their children the two semantic differentials noted above (consisting of identical scales) were compared to assess the percentage of the scales on which each woman rated herself and her child within one point of one another. The range of such accord within each group and the mean percent of accord for each group were then calculated. The II group revealed the greatest range, varying from a low of 13% accord for one participant (i.e., 13% of her ratings for herself were within one point of the ratings she gave her child on the same scale) to a high of 94% accord for another. In the II group the mean percentage of scales falling within one point was 53.2 (SD 26.64). The IU group displayed a narrower range of 43% to 75%, with a mean of 53.7% (SD 15.54). The results for participants in the IIU group revealed a broader range of 44% to 94% for the seropositive children, with a mean of 69.9% (SD 17.04); the range of accord with the seronegative children in this group was 31% to 87% with a mean of 65% (SD 18.55).

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Finally, the UU group displayed a range of 21% to 81% with a mean of 52.7% (SD 17.86). None of these differences were found to be significant. An analysis of variance performed on the mean accord scores for the evaluative dimension of these semantic differentials failed to reveal any significant differences (See Table 10). Nor were any significant differences found between the groups in a comparison of individual scales including Happy-Sad, Hopeless-Hopeful, Weak-Strong, Innocent-Guilty, Useful-Useless, Worthless-Valuable and Healthy-Sick (See Table 11 for scores on these scales for all groups).

Results from the evaluative dimension of the semantic differential "MY CHILD" revealed no significant differences in positive/negative attribution of the participants to their children. Women in the II group, who were hypothesized to rate their children most negatively, were shown to ascribe more positive meaning to their children than did women in the other groups to any of their children (See Table 12).

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Table 10: Mean Accord Scores on Evaluative Dimension of "MY CHILD" and "ME" Semantic Differentials

Group:	II				IU				IIU				UU			
	01		02*		01		02		01**		02		01		02	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
	0.20	0.42	N/A	N/A	0.10	0.22	0.20	0.45	0.30	0.48	0.20	0.42	0.20	0.42	0.33	0.58

* Women in II group each had only one child
** In IIU group 01 child is seropositive, 02 child is seronegative

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Table 11: Mean Accord Scores on Individual Scales of "ME" and "MY CHILD" Semantic Differentials

Group:	II				IU				IIU				UU			
	01		02*		01		02		01**		02		01		02	
Scale	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Happy-Sad	0.30	0.48	N/A	N/A	0.50	0.53	0.60	0.55	0.50	0.53	0.50	0.53	0.70	0.48	0.30	0.58
Hopeless-Hopeful	0.70	0.48	N/A	N/A	0.90	0.32	0.60	0.55	0.80	0.44	0.90	0.32	0.60	0.52	1.00	0.00
Weak-Strong	0.70	0.48	N/A	N/A	0.40	0.52	0.60	0.55	0.70	0.48	0.70	0.48	0.40	0.52	0.30	0.58
Innocent-Guilty	0.30	0.48	N/A	N/A	0.40	0.52	0.80	0.45	0.40	0.52	0.60	0.52	0.20	0.42	0.70	0.58
Useful-Useless	0.60	0.52	N/A	N/A	0.70	0.48	0.60	0.55	0.90	0.32	0.60	0.52	0.80	0.42	0.30	0.58
Worthless-Valuable	0.70	0.48	N/A	N/A	0.60	0.53	0.30	0.50	0.90	0.32	0.80	0.42	0.60	0.52	0.70	0.58
Healthy-Sick	0.50	0.53	N/A	N/A	0.30	0.48	0.20	0.45	0.90	0.32	0.40	0.52	0.60	0.52	0.70	0.58

* Women in II group each had only one child
** In IIU group 01 child is seropositive, 02 child is seronegative

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Table 12: Mean Scores on Evaluative Dimension of "MY CHILD" Semantic Differential

Group:	II				IU				IIU				UU			
	01		02*		01		02		01**		02		01		02	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
	40.7	2.58	N/A	N/A	37.9	3.90	33.2	6.14	39.0	3.40	36.1	5.13	38.3	4.90	38.7	1.15

* Women in II group each had only one child
** In IIU group 01 child is seropositive, 02 child is seronegative

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4. Evaluation of Body and Assessment of Disease Progression

The way in which the serostatus of offspring affected an infected woman's sense of her own disease process was evaluated using results from both semantic differentials and the Figure Outline task. II women were hypothesized to have a more negative subjective sense of their own bodies and to represent the disease as having affected them to a greater degree than infected women in the other groups.

These hypotheses were not supported by results from the evaluative dimension of the semantic differential "MY BODY." II women rated their bodies just as positively as did the other infected women. Though uninfected women scored slightly higher than did the infected women, there were no significant differences among any of the groups (II M = 27.7, SD = 5.70; IU M = 27.7, SD = 5.46; IIU M = 28.6, SD = 6.29; UU M = 29.2, SD = 3.74).

As shown in Table 6 there were no significant differences among the groups of infected women based on the Healthy-Sick scale of either of the semantic differentials "MY BODY" or "ME."

Results from the Figure Outline task were also used to assess participants' evaluations of the effects and extent of their disease. Consistent with semantic differential results, the expectation that women in the II group would regard themselves as most affected by disease was not substantiated by these results. As shown in Table 7, women in the UU group

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attained a mean location score of 2.2, significantly lower than the mean location scores for groups II and IU (II M = 11.5, IU M = 14.0, IIU M = 9.1). As reported above, there were no significant differences among mean scores of the groups of infected women.

Not included in the above location scores were colored body parts that had not been affected by illness but were expected to be affected in the future. These areas were specifically described by women during the drawing task as places in which they anticipated symptoms. Women in the IU group colored the greatest number of such places (44); women in the II group colored the second greatest number (11). No such places were indicated by either of the other two groups. Adding these scores to the above location scores yielded an even greater, and significant, level of difference between women in the UU as compared with IU and II groups [$F(3, 36) = 7.9286$, $p<.0005$].

Neither results from the three semantic differentials nor from the Figure Outline task substantiate the hypothesis that women in the II group feel that their bodies have been more affected by disease than do infected women in the other groups. Nor do the results suggest that women in the II group view their bodies more negatively than do women in the other groups.

The Figure Outline was also intended as a means of evaluating the extent to which illness was perceived as

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located in areas of the body associated with reproduction. The number of examples of drawings in which reproductive areas were definitively designated and colored was too small for statistical comparison. Women in II and IIU groups each designated two areas "ovary" or "uterus." Women in IU and UU groups each designated one such area.

DISCUSSION

The following discussion focuses first on the empirical and qualitative findings of this research. Limitations of measures and methods will be noted next; some observations as to ways in which these may have affected results will be included. My clinical impressions as well as the clinical significance of this work will then be addressed. Articulated and observed reactions of participants to the research protocol will also be reviewed here. Recommendations for additional research and clinical interventions conclude the discussion.

Discussion of Results

This study compared four groups of women in four primary areas of inquiry: use of denial as a psychological defense, characteristic affect level, identification with and assessment of offspring, and subjective sense of disease process. Multiple measures (semantic differentials, TAT,

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Figure Outline task and interview) were used to assess the groups in each of these domains.

1. Denial

The first hypothesis was that HIV infected women with infected children (II) would utilize denial to the greatest degree, especially in anticipation of the future and when confronted with the themes of motherhood and separation. Though findings were, in some respects, consistent with this hypothesis, based on all results, the conclusion that women in the II group used denial excessively was not supported. Indeed, there were only two circumstances in which women in this group appeared to use denial to a degree that apparently impaired other ego-functions. These two circumstances will be described below. Unexpectedly, it was HIV infected women with uninfected children (IU) for whom defense use may have been most problematic. Some results suggested what may amount to an insufficient use of denial by women in the IU group.

Denial use was measured in several ways: on the TAT; on the semantic differentials "The Future," "ME," "MY BODY," and "MY CHILD"; on the Figure Outline Task; and on two segments of the Interview section of the protocol. Results from each of these measures are noted and discussed below.

The II group of women evidenced more denial on the TAT than did the other groups of infected women, however, it was the uninfected control group (UU) that revealed the most

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instances of denial as well as the highest proportion of denial as compared with other defenses. The IU group of women used significantly less denial than did either the II or the UU group. That the defense use of the II group of women most closely resembled that exhibited by the UU group suggests that the extent of denial used by this group of infected women was not excessive - relative to the control group in this research.

In order to determine whether denial usage differed among the groups when themes of motherhood or separation were central, stories on specific TAT cards were compared. As anticipated, some cards evoked considerably more stories in which these themes predominated. No significant differences emerged among any of the groups on any of these cards, however. Moreover, the use of denial on these cards was not, overall, greater than the use of denial on other cards. Thus, even when confronting these emotionally charged topics, the TAT did not reveal evidence of excessive denial use for any group of women in this study.

Results from the interview section of the protocol did, however, suggest that excessive denial use among women in the II group may be evident in _behavior_ related to the issue of child-bearing. Although infected women who had only an infected child (II group) did not report that they intended to have additional children more so than did women in the other groups, their behavior (lack of use of contraception)

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contradicted this intention. Moreover, while the numbers were not significant statistically, it is of interest that the greatest number of women pregnant at the time of the interview were found in the II group. Given the dearth of other examples of excessive denial use, the possibility that denial may figure prominently in decisions with regard to child-bearing is striking. Literature cited in the introduction (Sherr, 1990) noted an increase in the pregnancy rate among HIV positive women as compared with sero-negative controls. The possibility that women in the II group may be particularly prone to become pregnant is of interest. The significance to women in this group of bearing additional children will be explored in more detail below.

Denial use in anticipation of the future was also expected to be greatest among women in the II group. Results based on the TAT did not provide much illumination with regard to this aspect of the hypothesis as there were so few examples of denial in the future segments of stories. The division of stories into past, present and future components proved to be problematic. This reflected, perhaps, a common reluctance to formulate an "ending" for stories; many of the future components of stories were quite sparse. Some stories ended in ways that were, likely, indicative of denial or avoidance but did not fit into any of the scoring categories identified by Cramer's (1991) system. One frequent reply to the question of what would happen in the future was "I don't know" or, a

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slightly more defensive version, "how should I know?" For many participants, a decline in organization, loss of distance from the card or abrupt distancing from the card marked the conclusion of stories. Some future components were simply less elaborated than the other components of the story had been. In and of itself, this is a notable observation though it does not contribute to the evaluation of the hypothesis regarding denial use among women in the II group in anticipation of the future.

Results from the semantic differential, "THE FUTURE" did not support the above hypothesis. The UU group of women rated the future most positively, but the group of infected women who came the closest to the positive ratings of the UU group was the IIU group (Infected women with both infected an uninfected children) rather than the II group. Of interest is the fact that the IU group of women rated the future most negatively - significantly more negatively than did the UU group of women. This is consistent with the possibility that these women may have more difficulty than the other groups of infected women in mobilizing defenses sufficient to sustain some hope.

Predictions regarding denial utilization were likewise not supported by results from any of the other semantic differential tests. The Healthy-Sick scale on "ME," and "MY BODY" semantic differentials revealed similar scores for the groups of infected women. The UU group's scores on these

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scales were consistently higher than those of the other groups indicating some degree of realism on the part of all the women. Additionally, consonant with the suggestion above that the IU group of women may have difficulty in mobilizing sufficient defenses, the scores of women in that group were, though not significantly, consistently lowest on these tests. Scores on the Weak-Powerful scale and evaluative dimension of the semantic differential "SICKNESS" also did not support the expectation that the II group of women would utilize denial to a greater degree than women in the other groups. Indeed, of all the groups of infected women, the II group rated sickness the most negatively and as being most powerful (i.e., the most realistic perspective and opposite of what was hypothesized). Additionally, on the semantic differential "MY CHILD" uninfected children received the highest scores on the Healthy-Sick scale, indicating the overall capacity for realistic assessment of the children's health.

Nor did findings on the Figure Outline task suggest greater use of denial by women in the II group than women in other groups. The II group of women scored between the other two groups of infected women on this task, and all three groups of infected women clearly depicted themselves as more affected by disease than did the UU group. Again, the IU group of women portrayed themselves as most affected by illness.

While, with one exception, the above results did not

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indicate an excessive use of denial on the part of women in the II group, some clinical observations of participants are of interest here. Just as the behavior of II women with regard to child-bearing may indicate denial which was not evident based on test results, so the behavior of II women with regard to their own health care may also evidence denial despite the dearth of empirically based findings. It was my impression that women in the II group appeared to neglect their own health care to a greater degree than did women in the other groups.

While many women in the sample displayed some reluctance in adhering to their own medical regimens, women in the II group seemed to be the least compliant. This lack of compliance was, perhaps, particularly obvious in that it contrasted so sharply with the generally scrupulous compliance shown to the children's medical regimens. Women who attended each and every one of their child's appointments were often quite lax in keeping their own. This behavior suggests a lack of acknowledgement of their own illness among women in the II group. Additionally, as mentioned above, though empirical findings did not evidence significant differences, a consistent trend among women in the II group to regard themselves as less affected by illness than did women in the IU group was observed. One possible interpretation of this observation will be offered below.

In sum, while women in the II group did use more denial

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and a greater proportion of denial on the TAT than did women in either the IU or IIU groups, their use of this defense did not, overall, appear to be excessive. The group using the greatest amount and highest proportion of denial was, in fact, the uninfected control group. Moreover, based on the breakdown of TAT stories by theme, it is evident that stories of motherhood and separation did not trigger a greater use of denial in any of the groups, including the II group. Nor did denial use as reflected on the other measures indicate statistically significant greater usage by the II group of women. There is no empirical evidence that denial impeded either an acknowledgment of the negative aspects of disease or realistic assessments of current and future effects of disease. The behavior of women in the II group around the emotionally charged area of conception suggested the possibility of excessive denial use. Observations of lack of compliance with medical regimens may also be indicative of extreme denial use within this group. The consistent tendency to regard themselves as less affected by illness than did women in the IU group is also of interest.

1. Affect Maturity

The II group of women was expected to exhibit the lowest affect maturity, particularly when confronted with themes of motherhood and separation. This expectation was not supported by affect maturity scores on the TAT. In comparing all TAT

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Cards, the four groups displayed remarkably similar affect maturity levels. The evidence regarding affect regression on cards eliciting stories of motherhood or separation was, at most, ambiguous. While the II group attained its lowest affect maturity score on Card 2 (which elicited many stories with prominent themes of motherhood), the IIU group's mean score was lower on this card. Moreover, Card 6BM also elicited many stories of motherhood yet affect maturity scores on this card were among the highest for all the groups (_the_ highest for both the IU and IIU groups). Nearly all stories told in response to Card 7GF contained themes of motherhood. On this card, again, however, there was no evidence of a regression in affect maturity scores for any of the groups. As for cards high in separation themes, scores on Card 6BM have already been noted; the other two cards high in this theme were numbers 3GF and 13B. On Card 3GF the scores for all groups were remarkably close to one another: all were within 0.1 of the overall mean score for that card. Nor were affect maturity levels displayed on Card 13B particularly notable for any of the groups.

Thus, cards which evoked many stories containing conflictual themes could not clearly be linked to lower affect maturity scores for any of the groups. Nor did findings suggest an overall lower characteristic affect maturity level for the group of II women.

The relative uniformity of affect maturity scores,

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hovering around a level of 3, was, itself, remarkable. Though the meaning of this uniformity in the context of this study cannot be conclusively determined, a brief re-examination of the characteristics of a level 3 affect maturity score may be illuminating. Thompson (1986) describes this level of affect maturity as being, normatively, quite low. Citing a lack of differentiation between one's own emotions and the emotions of others as one aspect of this level of affect maturity, Thompson (1986) writes that a person functioning within this level has, "no understanding that two people may experience the same emotion but for their own individual reasons" (p. 215). Thus, emotions are understood in a highly egocentric way. "Outer reality and the affects of others [are] taken as a reflection of one's own inner state" (Thompson, 1981, p. 222). Though contradictory emotions may be expressed, they remain "largely independent" of one another and do not interact. Additionally, the affect-state is irreversible, and both self and object representations are evaluated in terms of the affect-state, rather than being recognized as having independent characteristics. Finally, Thompson (1986) notes that affect tolerance at this level is limited. She writes, "If an unpleasant emotion is experienced, it will color all reality for the moment and the perception of self and other within the reality" (p.222).

A conclusive explanation of the consistently low affect maturity scores obtained by participants in this research is

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not within the realm of the present work. The possibility that the extraordinary stress of living with HIV may cause a regression in affect maturity is undermined by the fact that the uniformity of scores extended to the UU group of women. Thus, one must wonder whether some other facet(s) of life shared by participants across groups may be related to such a relatively low level of affect maturity.

Regardless of why the affect maturity level was so low, the fact that there was such consistency suggests that the findings may extend beyond the sample who participated in this work. The implications of such affect maturity level in terms of capacity to participate in healthy, reciprocal, nurturing relationships may be profound. These results, then, while they do nothing to distinguish between the groups as delineated in this study, and do not even distinguish HIV infected women from seronegative women living in similar circumstances, are important nonetheless.

3. Identification with and Assessment of Offspring

Women in the II group had been predicted either to over or under-identify with their children and to rate them the most negatively. Both in terms of identification and evaluation, women in the IIU group were expected to distinguish between their children according to their serostatus. While some findings from both the semantic differentials "ME" and "MY CHILD" and the interviews were

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consistent with the above hypotheses, others were not.

In comparisons between the two semantic differentials to determine the extent to which participants identified with their children, the group of II women displayed the greatest range (i.e., most similar and most dissimilar). The standard deviation for this group was greater than that of any of the other groups. This suggests an identification pattern that touches the extremes (i.e., over or under-identification) and would thereby be consistent with the results predicted. Contrary to expectations, however, the UU group displayed the second greatest range in ratings, suggesting that such extremes in identification may not be related to HIV status. Moreover, results did not show that women in the IIU group identified with their children according to serostatus. Comparisons of mothers and children on individual scales (e.g. Happy-Sad) failed to reveal any differences among groups in feelings of similarity - or dissimilarity - in terms of specific characteristics or qualities.

The interview section of the protocol provided additional data regarding the extent to which participants felt their offspring resembled them. Most women saw in their children characteristics associated with both mother and father, as well as other relatives. Only five women expressed a belief that their children were similar to them in every respect. All of the children described in this way were seronegative - two mothers were from the IU group, and three from the UU

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group. A total of eleven participants responded unequivocally that their child bore them absolutely no resemblance. Of these eleven, none of the women were in the UU group, only one was in the II group, four were from the IU group and six were from the IIU group. Of the children from the IIU group described by their mothers as bearing them no resemblance, only one was seronegative. Thus, half of the women in the IIU group cited their infected children as bearing no resemblance to them, and only one out of ten regarded her uninfected child that way. Thus, despite the lack of distinction between seronegative and seropositive siblings based on semantic differential data, material from the interview section of the protocol revealed a tendency among women in the IIU group to cite their seropositive children as dissimilar from them. Moreover, all five children regarded as resembling their mothers completely were seronegative. Only one mother described her seropositive child as absolutely resembling her. Consistent with speculation in the introductory section of the present work, this suggests that HIV infected mothers may be inclined to resist identification with their HIV positive children.

Quite unexpectedly, women in the II group rated their children the most positively of all the groups. Consistent with this finding, women in the IIU group evaluated their seropositive children more positively than their seronegative children. The children who were evaluated the most negatively

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were the seronegative siblings of seropositive children. These children, besides being rated most negatively on the evaluative dimension, were also considered by their mothers to be "weaker" than their seropositive siblings. These findings concur with frequent interview comments by women in the IIU group referring to their seropositive child as "my special one." Thus, the data seems to reflect some idealization of the infected children. This idealization may itself assist in sustaining an attachment between mother and child.

These findings regarding identification and evaluation of offspring do not contradict the expectation presented in the early pages of the present work that HIV positive children may evoke in their mothers a heightened awareness and fear of their own mortality. Another explanation may be that the apparent difficulty with identification reflects the contrast between the way in which these HIV infected women regard themselves and their idealization of their children. Accord scores on the evaluative dimension of the "ME" and "MY CHILD" semantic differentials did not, however, support this interpretation.

4. Evaluation of Body and Assessment of Disease Progression

The II group of women, expected to regard their bodies most negatively, did not do so. The scores of this group on the evaluative dimension of the semantic differential "MY

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BODY" were comparable to the scores of the other groups of infected women. Indeed, though the UU group of women rated themselves most highly on this scale, they did not do so to a significant degree. The infected women seemed, thus, to regard their bodies relatively positively despite the fact of their HIV.

As was expected, the UU group of women rated themselves as most healthy on the semantic differentials "ME," and "MY BODY" and obtained by far the lowest (least affected by illness) scores on the Figure Outline task. Unexpectedly, -- but consistent with the suggestion above that this group may have difficulty in mobilizing sufficient defense -- it was the IU group of women, rather than the II group who rated themselves as most sick on the semantic differentials and as most affected by illness on the Figure Outline task. Moreover, the IU group of women anticipated the development of far more symptomatology in the future than did either of the other groups of infected women.

Women in the II group, having transmitted the virus to their children, were predicted to locate illness in areas of the body associated with reproduction more so than would women in the other groups. Results from the Figure Outline task were not conclusive with regard to this issue, however. In many cases drawings were too ambiguous to definitively determine whether reproductive areas were intentionally colored. Few women verbally specified that reproductive areas

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of their bodies were affected by illness. Only one woman commented on her coloring of body parts associated with reproduction. This participant, a member of the IIU group, said, "That's where everything took place as far as the illness beginning. It affected that area completely - the uterus and vagina." Comments during the interview did not address this issue; questions as to the extent to which HIV had specifically affected reproductive organs and the chances of transmitting HIV to future children would likely have elicited more pointed comments on this topic.

The correspondence between II women's assessments of illness affecting areas of the body associated with reproduction and their physicians' assessments was particularly low. While this seems to support the hypothesis in suggesting that there was little medical confirmation for feelings among women in the II group that reproductive areas of the body had been affected by HIV, the small numbers and ambiguity of drawings necessitate an extremely guarded interpretation of this finding.

Correlations between physician and patient drawings were, for all groups, remarkably low. Participants consistently represented themselves as far more affected by illness than did physicians. Indeed, scores on the Figure Outline task for the IIU group of women and their physicians were negatively correlated. This result is consistent with Chung and Magraw's (1992) study in which HIV infected women reportedly expressed

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concern as to whether medical caregivers believed that their symptoms were, "serious, real and medically significant."

Thus, semantic differential tests and the Figure Outlines did not suggest that women in the II group regarded their bodies any more negatively than did women in either the IU or IIU groups. Nor did findings show that women in the II group believed that they were more affected by illness or that areas of the body associated with reproduction were more affected. Unexpectedly, women in the IU group regarded themselves as most affected by illness - and anticipated the most symptomatology into the future. These findings will be discussed further below.

Limitations of Measures and Methods

1. Measures

TAT - As noted above difficulties were encountered in attempting to partition stories into past/present/future components. Though this did not reflect a limitation in the TAT itself, it may point to a problematic aspect of Cramer's (1991) defense scoring system. Some of the ways in which participants responded to the request for a future segment to their stories seemed indicative of denial although they were not scorable within Cramer's (1991) scoring system.

Affect Maturity - The relative uniformity of affect level among all of the groups in the present study was unexpected. The lack of significant difference between the UU group of

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women and the groups of HIV infected women was quite surprising. Perhaps my expectation that extreme stress would cause a regression in affect maturity was inappropriate. In any event, the results of the scale are so uniform as to lead to questions regarding the ways in which commonalities among all of the participants including the women in the UU group may impact on affect maturity level.

While these findings may have clinical meaning which cannot be conclusively determined at this time, they may be related to the affect maturity scale in some way. The question must be raised as to the accuracy of the results. I cannot identify any aspect of either the administration of the TAT, the circumstances of the meeting, or the scoring of the protocols using Thompson's (1986) affect maturity scale which might have jeopardized the accuracy of results.

Semantic Differentials - During the administration of this measure some participants verbalized portions of their thought processes. The insight this provided into the ways in which different participants approached the task led to the identification of a possibly problematic aspect of this measure. Quite clear on the semantic differential, "THE FUTURE," comments by participants evidenced the extent to which hopes, wishes, fears and superstitions entered into the task. For example, one participant looked at a scale and said, "Well, I hope I'll still be healthy in the future but since it's unlikely I'll check the middle" while another

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noted, "I hope I'll be healthy in the future so I'll check it here on the healthy end even though I'll probably be getting more sick." Many women seemed reluctant to put pen to paper in marking their negative beliefs out of a superstition that this might make those fears come true; defining themselves as healthy in the future, some felt, might make it so. Others would not acknowledge hopefulness in written form out of a fear that this would bring on the equivalent of the "evil eye." Thus, the comments these women made, usually to themselves, during the task lent insight into the inappropriateness of strict interpretation of the meaning of the results of the scales. Not all of the women did comment aloud, however, and, unfortunately, it was not part of the protocol to question each participant on her approach to the task. The comments testify both to the difficulties with the assumption that any task is approached identically by every person, as well as to the complexities inherent in the presentation of self.

Despite the room for personal interpretation of each concept and each scale, results from the semantic differentials were consistent with findings based on other measures. The semantic differential results, however, failed to reach significance even when results based on other measures of similar concepts did so. One illustration of this was in the Healthy-Sick scale of the semantic differential "ME" as compared with the Figure Outline task. Results from

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the two measures showed the same overall relation among the groups; both measures showed the UU group, for example, as the least affected by illness. The Figure Outline task found, however, a significant difference between that group and the group most affected by illness, whereas the semantic differential did not. The direction of difference revealed by the semantic differentials was internally consistent as well; for example, the group of UU women invariably rated themselves as healthier than did the infected women. The lack of any statistical significance is notable and leads one to wonder at the usefulness of this measure with small samples. The difficulty mentioned above may have contributed to this as well. The "room" in the semantic differential for wishfulness may have skewed results in such a way as to minimize the differences among groups though maintaining the overall relation of the groups.

Figure Outline - One aspect of the scoring of this task proved to be problematic due to the sometimes ambiguous nature of the drawings. In a few instances it was not possible to determine precisely which area of the body a participant had intended to designate as affected by illness. While in the latter meetings the author asked participants to name the areas that they had colored, in the early interviews no such questions were asked. The ambiguity of drawings posed some difficulty in addressing the question of the extent of connection between illness and areas of the body associated

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with reproduction. Some women specifically said that colored areas were meant to indicate the "Uterus" or "Ovaries," most, however, did not. There were a number of drawings in which it was not at all clear whether the colored areas were meant to designate the abdomen or pelvic region. Additionally, in many drawings the genitals were colored; given the frequency of Candida vulvovaginitis in HIV infected women, this could not be understood (or scored) as an area associated with reproduction, though in some cases it may have been. If this measure is used in the future I recommend either that the administrator ask each participant to name the colored areas or that a checklist of body parts be provided as a companion task. Severity of effect could also be indicated on the checklist quantitatively with, for example, a 1, 2,or 3. This latter would also serve as a check of the accuracy of the drawing. When areas which appear to be associated with reproduction are indicated either on the drawing or checklist the administrator might ask, "Do you think this affected or would in the future affect the likelihood of transmission of illness to your baby?" Finally, none of the women in the UU group had a regular health care provider; thus, figure outlines colored by physicians were not obtained for this group.

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2. Methods

The number of participants in this study was slightly smaller than had been anticipated. To some degree this was due to the size of the population available through the clinic (the exclusive source of participants). A great many of the children attending the clinic were in foster care which limited the number of biological mothers available for recruitment. Probably the most significant factors in the smaller sample size, however, were the various logistical obstacles encountered by women in actually keeping appointments with me. In lives which combine obligatory attendance at multiple appointments, with various people, at multiple agencies, with an often inadequate support network, one additional, optional, appointment may feel both trivial and overwhelming. The protocol proved too time consuming and emotionally involving to be administered during the regular waiting period at the pediatric clinic. Thus, separate appointments were required. Though child care was provided during these meetings, the very task of making an additional trip to the hospital proved insurmountable for some. Twenty one women did not attend their first appointment with me; six of these missed their second as well, and three of the six also missed a third appointment but attended the fourth. Many of the women recruited for the study lacked telephones which made the confirmation of appointments and rescheduling of missed appointments especially difficult. While letters were

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mailed by the author when phone contact proved impossible, responses to mailed reminders were unreliable. When an appointment was missed, I often had to wait until the child's next scheduled pediatric visit to reschedule a meeting with the mother.

Sixteen women initially consented to participate but did not do so. Nine of these women, after missing at least two scheduled appointments, maintained that they wanted and intended to participate but various factors made this impossible. Such factors included conflicting appointments with public assistance workers regarding various benefits such as WIC and disability, meetings with Bureau of Child Welfare Workers, attendance at drug rehabilitation programs, appearances in Family Court, medical appointments requiring unanticipated periods of waiting, and hospitalizations of either the participant or her child. Ambivalence about taking part in the study was certainly a factor for some of these women, but this seemed to serve to delay rather than prevent participation.

Explanations of non-participation for the women who did not continue to express interest after an initial consent, and for those women who never did consent to participate were varied. Of the women who consented but did not eventually participate, most would have been in the UU group. These women did not appear to have the same health pressures and restraints as the infected women; they did, though, bring

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their children to clinic far less frequently than women in the other groups. Thus, their appointments were generally only once every six months. A missed appointment with such a woman, who might not have a phone, meant much more difficult follow-up and less likelihood of repeated rescheduling.

The reasons for outright refusal to participate were not always clear though in three cases it seemed a matter of logistics: two women felt they could not take the time from work, another lived quite far away from the hospital. One woman declined to discuss her refusal but appeared, much of the time, to be quite overwhelmed in coping with the stresses of her own and her child's illness.

In the course of interviews with participants, a number of variables emerged as potentially important factors in the adjustment to and attitude toward HIV. These variables could not, given the size of this sample, be accounted for fully. A couple of these will be mentioned here as they may, in future studies with larger samples, bear attention. The first such variable was the extent and type of contacts participants had had with others infected by HIV. Some women were heartened by distinctions drawn between themselves and those they had known in whom HIV had progressed rapidly. Two examples of such sentiment follow: "She died real fast but she never took care of herself;" and "She kept doing drugs even after she got sick." Needless to say, parallels participants noted between their own symptomatology and that of someone

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they knew who had subsequently died was cause for alarm. Some women had not had any personal contact with anyone with HIV and seemed only to be learning about the virus through their own experience. Some participants were encouraged by anecdotes regarding people who continued to live years and years after their diagnosis; others were not. In sum, the impact of such experiences is clearly important and worthy of direct inquiry in future research. Another such variable, not unrelated to the first, was the subtleties of meaning of symptomatology to each participant. Though the groups were well matched in terms of numbers of "symptomatic" vs "asymptomatic" women and children, for some "asymptomatic" women a particular minor ailment may serve as a recurrent reminder that all is not well - due to any number of associations she might have. Besides the importance of inquiry into the significance for participants of these "minor" symptoms, also relevant is the specific state of health of both participant and offspring at the time of the interview. A minor cold in a child might for one participant cause little anxiety; for another who's child went on in the past to develop a pneumonia following a cold, such a "minor" event might be quite alarming. The meanings of symptoms, both major as well as minor, are certainly multifaceted and worthy of careful exploration.

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Clinical Impressions

This portion of the discussion draws primarily from the interview section of the protocol; observations of participants as well as relevant empirical data generated from this work are also included. Both commonalities and differences in the experiences of HIV infected women are considered. While the lives of the thirty HIV positive mothers who participated in this study reflected an enormous diversity of experience in some respects, decided commonalities did also become apparent through this work. Some distinctions among women appeared to be related to the serostatus of offspring though not all in the ways anticipated at the outset of this research. Other differences which became evident were unrelated to offspring serostatus and seemed, rather, to reflect individual variation.

Beginning with an overview of participants' responses to their diagnoses of HIV and the range of adjustment to and attempts to cope with that diagnosis, this discussion then addresses some of the less adaptive aspects of defense use observed among participants. A comparison of some features of the experiences of women in the II and IU groups suggests possible clinical vulnerabilities of each group and concludes this section of the discussion.

Based both on participants' accounts of their own experiences as well as on my observations of mothers attending the Clinic, some continuum of adjustment following the HIV

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diagnosis was evident. This continuum appeared, in the most general way, similar to that described in the introduction as typical of parents who have a child with cancer (Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1965; Bornstein & Klein, 1974; Chodoff, Friedman & Hamburg, 1964; Friedman, Chodoff, Mason & Hamburg, 1963; Futterman & Hoffman, 1973; Gogan, O'Malley & Foster, 1977; Natterson & Knudson, 1960; Richmond & Waisman, 1955; Slavin, 1981). Most HIV positive mothers seemed to move from an initial state of shock and devastation which was extraordinarily disorganizing psychologically and debilitating physically to one of more stability and control. The degree to which this adjustment reflected an actual integration of the diagnosis as opposed to a precarious and temporary bolstering of defenses was variable, however. There is reason, described below, for concern as to the enduring ability of many of these women to sustain this level of adjustment in the face of continually stressful life circumstances.

Many participants described the initial period following their diagnosis as one during which they were overcome with despair. Commonly, suicidal thoughts prevailed for a short time. One participant described feeling during this time that, "the world was caving in." Many spoke of crying until they simply could not cry any more - sometimes for days at a time. Some women told of fleeing (literally) until they had calmed down. Some, having been "clean" for long periods,

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returned to drug use. Women whose children were diagnosed at around the same time as they were themselves, often described feeling that they could handle their own diagnosis but that the diagnosis of their child made them "crazy." Many participants described combatting the despair which characterized this period with a conscious effort to regain some composure for the sake of their children. Motherhood, a sense of obligation to offspring, was, thus, broadly cited as motivating, even in the worst of times.

Several factors seemed to mediate the reactions of participants to their diagnosis of HIV. The circumstances surrounding the diagnosis was the most obvious of these. Some women, having realized the extent of their risk, chose to be tested. Others became ill unexpectedly. Others, feeling fine, had a child who became ill and was diagnosed. Thus, for some women the diagnosis was anticipated; for others it was utterly shocking. The reactions described above were typical of the women for whom an HIV diagnosis was not consciously anticipated. By and large women who were infected via needles used for intravenous drug injection were least surprised by their diagnosis. Some participants asserted that they had "known" of their positive status before being tested; others said they had suspected it. Deciding to get tested was, for these women, a decision which reflected a readiness to have their suspicions confirmed. Following these initial reactions to the diagnosis of HIV the spectrum of responses

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and experiences broadened further.

The extent to which participants had disclosed their HIV status to others varied widely. Some women had told not only family and friends but had spoken in educational forums to groups of strangers about their experiences with HIV. Some had confided in no one. The reasons participants gave for their choices regarding extent of disclosure varied tremendously. Some participants feared rejection or intolerance by family and friends; others feared pity. One woman noted that she could not tolerate "the worried look." For these women, compassion often made it more difficult to keep their own feelings at bay (something they tried valiantly to do). Some participants had been spurned either directly or more subtly and had since ceased sharing their diagnosis. For some the decision not to share the information was described as a matter of privacy. One participant said simply, "it's no one's business." Many heterosexually infected women expressed discomfort with the possibility that an open acknowledgment of HIV status would label them as drug users. One such participant noted that she was reassured by the knowledge that, "Lots of people have it. Not just drug dealers get it -- also Doctors, Lawyers -- you can't tell who has it. People can't know I have it unless I say so." For some women, discussing HIV was so uncomfortable that they referred to their experiences without ever verbalizing "HIV," "Virus," or "AIDS." One such woman simply said, "what I

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have," "it," or "that thing" throughout our discussion.

Just as limited disclosure had a range of meanings for participants, so did the decision to tell many people. For some women broad disclosure reflected a search for support; for others such sharing was an act of defiance against their family's wish for secrecy. Still others disclosed their diagnosis as an assertion of their own acceptance of the disease. Some participants described being comfortable with the extent to which they had shared their diagnosis. For others, this was a continual source of pain - either because they felt isolated in their silence; or, just as often, because they felt isolated in their openness.

The level of support received, clearly linked to the extent of disclosure, depended on other factors as well. Circumstances not directly related to the illness undermined the potential support network of many women. For some participants prior drug use had severed familial and social ties. For others, family had longsince been fragmented by violence, illness, poverty and loss and could provide no comfort. Several women noted that they had always been the family caretaker and, though overwhelmed by the role, could see no way out. Ill partners and children, the various and multiple appointments at social service agencies, the worries about money, housing and health-care overburdened many women to the extent that they had not attempted to seek emotional support from any source. Some women had longsince become

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accustomed to handling crises alone and, thus, continued to deal with their emotions in private. When asked how they dealt with painful or troubling thoughts and feelings, some techniques described included: turning music up as loudly as possible, and going into the bathroom to scream. A great many women described simply trying to block out painful or troubling thoughts - with varying success. One participant said,

> I try not to think about it but when I'm by myself it's <u>all</u> I think about. I try to do something so I don't have to be thinking about what I'm thinking about. I try to do something. If it doesn't work I go to sleep or something so I don't have to worry about it. It's pretty hard. I'm always looking for something to <u>block</u> what I'm thinking.

Another noted, "I try to ignore things. I don't want to think about it. It pops up in my head. I push it away as fast as I can. I try to think only about <u>good</u> things." Some justified this behavior by explaining that they believed to remain healthy a "good" attitude and outlook were essential. As one participant stated, "I try not to think about the future. I take my pills like vitamins. I'm afraid if I get scared I'll feed into it. I'll fall, get weak, get worse." Minimization of the significance of the virus was also evident in some women. Regarding her HIV infection one participant said, "It's not the end of the world or anything;" another, "I have the virus. A little tiny one."

Despite these and other obstacles many participants <u>had</u> sought support from a variety of sources including therapists,

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formal and informal support groups, social workers at various agencies, friends and relatives. While some women expressed satisfaction with both the emotional and concrete support available to them, the majority did not. Many women regarded their attempts to cope with feelings as unsuccessful. Some described a persistent depression. Others spoke of feeling angry all the time. A few women spoke of feeling constantly irritated by small things that would not, previously, have bothered them. Some participants worried about taking such anger and irritability out on their children.

A few participants described a feeling of emotional stability and contentment with their adjustment. These women reported that since their diagnosis they had begun to regard life with an enhanced appreciation. They portrayed themselves as having adopted a more positive attitude and active, "take charge" stance. One such woman stated, "Since I found out, I feel I have a more quality life -- doing worthwhile things -- teaching other people." Another woman noted,

> If you're in the right frame of mind you should be able to get on with life. It [HIV] makes life more special. Things you didn't look at before you look at -- like squirrels, birds -- everything is special. When you know you're going to lose something it makes it more special. You have to keep the will. Every day is special...

The small numbers of women in this sample who expressed such sentiment is particularly troubling given recent research pointing to positive attitude, hope, and active coping style as "strong attributes of long-term survivors of AIDS" (Fawzy, Fawzy & Pasnau, 1991). Depression, stress and lack of control

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have all been associated with some degree of immunosuppression (Ickovicks & Rodin, 1992).

Participants in this study displayed a broad range both in their methods of coping as well as in the efficacy of those methods. While all of the participants were, as noted above, able to overcome the initial massive shock and despair which often characterized the period just following diagnosis, some revealed, most obviously in their responses to TAT cards, a continuing and worrisome vulnerability to stressful circumstances.

The many unelaborated, self-referential, distant and disorganized stories told by participants suggested some inadequacy in their psychological defenses. Disruptions in responses varied both in form and degree. For some women commentary regarding the card itself, for example the quality of the drawing or the time period depicted, provided enough distance to enable the narration of a coherent story. For others, such remarks themselves prevented such coherence, serving only to disrupt the narrative. Some participants repeatedly "forgot" the task and were consequently unable to render a fully elaborated and intelligible tale. Many powerful and disturbing stories were interrupted by inappropriate and self-conscious reactions. One participant, for instance, stopped in the midst of a painful story and began to laugh saying, "I got the giggles." She did not resume her recitation where she had left off. Another

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participant, mid-tale, became dizzy and needed to take a break. Some stories were punctuated by momentary losses of distance in which, often, a "she" became an "I." For a number of women this loss of distance was occasionally more persistent and disruptive. In such instances, whole stories became completely autobiographical with the participant leaving the card entirely behind.

Thus, defenses were unable, under some circumstances, to protect participants from painful affect while fully preserving cognitive function. For some women this resulted in a deterioration of intellectual ability evidenced by a lack of coherence in stories. For others this meant that while stories were intelligible, they lacked elaboration. In other cases defenses seemingly failed altogether resulting in emotionally overwhelming responses relating only obliquely to the card. (In such instances the administration of the TAT was suspended in order to discuss the issues which had arisen and allow the participant to regain her composure).

Whether this apparent weakness in ego function may be related to the groups of women as defined by this study is not entirely clear. Some observations from both the interview portion of the protocol as well as empirical data do, however, point to a clinical hypothesis which suggests that some entirely unanticipated differences between the experiences of women in the II and IU groups may be relevant here.

Defense use had been hypothesized as most problematic for

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women in the II group; these women were expected to use denial excessively. With the possible exception of two specific circumstances (health care and contraception), neither empirical nor qualitative data supported this hypothesis. Women in the II group did, however, appear to mobilize denial adaptively. This is to say that participants in this group used denial to a degree sufficient to sustain hope without an impairment of ego functions. Denial use by women in the IU group was quite different. These women employed less denial on the TAT than did participants in any of the other groups. Indeed, they used significantly less of this defense than did women in the II and UU groups. Women in the IU group, moreover, assessed the future and their health most negatively, and anticipated by far the most symptomatology in the future. Though not significantly so, women in the IU group also rated themselves more negatively than did any of the other groups of women on the evaluative dimension of the semantic differential "ME." IU women were not able, perhaps, to utilize denial sufficiently to sustain the small measure of hope noted in the introductory section of this work as integral to functioning without becoming overwhelmed by despair or anxiety.

The hypothesis regarding defense use noted above had been based on certain assumptions about the ways in which the serostatus of offspring would affect the experiences of participants. The hypothesis appears to have been accurate

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in suggesting the centrality of motherhood for all of the women. This very centrality defined some of the more important ways in which the experiences of women in the II and IU groups differed. While data and observations from this study do, then, suggest that the experiences of women in the different groups diverged, the ways in which they did so were not all consistent with expectations.

The circumstances of women in the II group had been presumed to be the bleakest of all the women. As described in some detail in the introductory section of the present work, the interaction between a mother's own illness and that of her child was expected to complicate and worsen the mother's adjustment to her own disease. Observations suggested that among women in the II and IIU groups care of and concern for the HIV infected children was, indeed, consuming. The tremendous concrete and emotional needs of these children appeared, however, to ease rather than augment the women's negativity about themselves in two ways.

First of all, the attention demanded by HIV positive children served, it seems, to deflect their mothers' focus away from their own illness. These women considered themselves to be healthier than did women in the IU group. This perspective is consistent with the observation, noted above, that women in the II group were especially lax in compliance with their own medical regimens. It is consistent as well with findings from a 1993 study conducted by Andrews,

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Williams and Neil which found that many HIV infected mothers, "seem to feel better about themselves for their ability to provide adequately for their children, especially when these children are also seropositive" (p.196).

A prime objective noted by many of the women in the II and IIU groups was to make the remainder of their ill child's life as happy and "normal" as possible. Most seemed relatively confident that they would achieve some degree of success in this endeavor. Perhaps this afforded them some sense of satisfaction, a positive feeling with regard to their own mothering abilities. Additionally, and quite unexpectedly, some idealization of the HIV positive children by their mothers was not uncommon. This idealization facilitated, perhaps, an ongoing intense attachment to the children and a continued investment in the future despite the threat of imminent loss. Hence, the second way in which care for seropositive children may have had positive effects: the enhanced sense of purpose in caring for their children along with such idealization may have contributed to improved self esteem as well as a greater feeling of maternal pride and confidence in these women.

Thus, the limited contraceptive use among women in the II group, initially understood as evidencing the dual desires of proving one's own health through producing a healthy child and leaving some proof of one's existence behind, must, perhaps, be reinterpreted. This behavior may also be seen as

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indicative of the extent to which the care of a child, specifically a sick one, serves to confirm the mother's sense of her health as well as her importance. The death of a child who's existence has served such a purpose may bring the mother's own mortality to the fore in an alarming fashion. Nonetheless, while the child survives, the mother appears to be buttressed against some of the anxiety for herself and despair for the future which the disease process might otherwise inspire. This then may provide an extremely powerful motive for procreation. Indeed, the intensity of the wish to reproduce is highlighted by the observation that evidence of excessive denial use among women in the II group was not found in the results of measures such as the TAT and Semantic Differential Test. The use of denial here, to enable conception in spite of rational arguments against it, suggests the depth and breadth of the function of offspring to these women.

The idea of being physically present for their children seemed to be of profound importance to most of the women included in this research. Women in the II group seemed to assume that either their child would die before them or that death would be somehow simultaneous. Being present throughout the life of the child represented, perhaps, good and committed mothering. Thus, women in the II group may not have been as troubled by fantasies of their children "left behind" as were women in the IU group. Despite whatever

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feelings they may have had about the transmission of HIV to their children, despite the potential emotional pitfalls of the interconnectedness of their own and their child's illness, these women may, for the most part, have been able to experience themselves, as mothers, in a generally positive light.

The preceding paragraph denotes, perhaps, the greatest and arguably most important difference in the experiences of women in the II versus the IU groups. Women in the IU group had been expected to find some solace in the achievement of a measure of symbolic immortality; in the form of a healthy child they would leave proof of their existence. The massive concern felt by most women in this group as to what would become of these children, left behind and motherless, appeared to prevail over the satisfaction and even relief which had been expected to result from this seemingly positive aspect of their situation.

The impossibility of accompanying their children into adulthood and witnessing future accomplishments was a source of profound disappointment for most women in the IU group. The primary source of anguish for many of these women, however, seemed to relate to the impact their absence would have on their children. Even those women who had made careful arrangements for the care of their children expressed an acute and painful awareness of the loss that these children would endure. The future these participants projected for their

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children was often one marred by the absence of a mother. As one woman put it, " She won't have a mom. She'll be alone in that sense. How will she grow up without me -- accomplish her goals. She's the one I'm going to leave behind. I worry so much about her." This very absence, may, perhaps, have been construed by some women as a failure in mothering.

Apprehension regarding the prospects of their children was compounded by the perception many participants had of the world as a cold and uncaring place. These women, perhaps due to their own experiences of struggle and isolation, did not envision their children embarking on a journey in which support, help, love and attention would be forthcoming. Many of them hoped, before they died, to endow their children with a kind of force-field consisting of confidence, information, and common sense with which to move into the future.

Responses to the interview questions, "How do you see yourself in five years?" and "How do you see your child in five years?" as well as queries as to participants' greatest source of concern and greatest difficulty in mothering, illustrated some of the ways in which women in the IU group hoped to maintain a presence for their children into the future. More often than describing the concrete plans for their children's welfare - the financial aspects or the question of who, exactly, would become primary caregiver - these women spoke of the need to convey crucial bits of wisdom to their children. Along these lines, one woman said, "Will

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I be able to show my kids the difference between right and wrong? Can I be a good teacher, provider for my kids? Can I take care of them until they're able to take care of themselves?" Another participant noted, "I'm not going to be here forever. I've got to do all I can in a short time...I'm trying to teach her right from wrong." And when asked about her greatest worry another participant replied, "Leaving my children alone. Dying before they're old enough to fend for themselves. It's the only thing I think about. It's always on my mind." The articulated concerns of these participants clearly focussed on the importance of such teachings for their children's ability to move successfully into the future. Also at stake was the unspoken but possibly pivotal anxiety for these women of whether they would feel that they had been able to adequately mother their children.

Thus, the combination of illness in both mother and child found in the II group, presumed to be disadvantageous, while certainly problematic in some respects, may, in other ways, have been beneficial for mothers. Women in this situation, with their attention deflected from their own physical ailments, experienced themselves as less affected by illness than did women in the IU group. Furthermore, women in the II group seemed more likely than did women in the IU group to achieve a measure of maternal pride and satisfaction. Whatever gratification there may have been in the expectation of a measure of symbolic immortality was, apparently,

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outweighed by the disadvantages of the anticipation of actually leaving a child behind. Women in the IU group experienced the future as more bleak than did women in the II group. Those mothers in the IU group seemed to perceive the future as defined by their absence and may, thus, even have experienced their own disease process, in some sense, as a slow abandonment of their children.

The extent to which participants felt comfortable with themselves, with their diagnosis, the extent to which they felt supported emotionally and concretely, varied hugely. The ways in which they confronted daily stresses, the details of their lives -- both concrete and emotional - differed. What varied little among the participants in this study was the centrality of motherhood. A deep and uncompromising commitment, a fierce attachment to and protectiveness toward offspring were shared by all the groups of women. The very centrality of motherhood pointed, however, to the necessarily stark contrast between the experiences of women in the II and IU groups. Findings from this work suggest the possibility that the feeling of having mothered "well" may be a key ingredient in adaptive coping among HIV infected women. Research regarding the reproductive decisions made by HIV infected women (Kurth & Hutchinson, 1990) supports this finding. These authors write, "Motherhood is very important to the majority of women in our sample and for some, constitutes the primary source of self-expression and self-

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esteem" (p.125). Interviews with HIV infected women conducted by Williams (1990) also support both the centrality of motherhood and the importance to HIV infected women of being a "good mother." The circumstances of women in the IU group appear to make it more difficult for such women to feel positively about their mothering; this may be related to the greater negativity as well as the seemingly less adaptive use of defenses exhibited by this group.

Reactions to Participation

While participants approached the meeting with a wide range of attitudes and expectations, the near uniformity of response to the initial contact was remarkable. Most women reacted to recruitment efforts with striking enthusiasm.

This enthusiasm may have been due, at least in part, to the lack of opportunity for emotional expression in the lives of so many participants. Many women viewed the meeting as a rare chance to share their experiences, worries and feelings and used it as such. A few women, those who were perhaps more supported and more practiced at verbalizing their experiences, chose to participate out of what they described as "curiosity". Others expressed a desire to contribute to the research in order to "help others."
Some participants answered questions during the interview with brevity, others elaborated their answers as fully as possible.

Participants' emotional expressiveness during the meeting

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encompassed a broad spectrum. A few women remained impassive throughout. Some of these responded in a relaxed manner indicative, perhaps, of the extent to which they had already become familiar and comfortable with the issues at hand. Others who betrayed little emotion did so, it appeared, out of a self-protectiveness, a restraint which suggested some difficulty in verbalizing their more painful feelings. At the other extreme, a few women became highly emotional in the course of the meeting. Among these women, some seemed lacking in emotional boundaries; these participants had difficulty in discussing specific aspects of their experience without becoming consumed by emotion. For a majority of the women who participated in this research, however, the level of emotional expression fell somewhere between the two extremes noted above. Most women did display much affect, usually appropriate and sometimes quite raw.

The range of responses elicited by the protocol likely reflected many factors including participants' defenses, level of emotional need, style, transference to the clinic, and the state of their own and their children's health the day of the interview. Though nearly all of the women regarded the meeting as having been helpful to them in some way, those who were most reserved seemed to find it less beneficial than did those who were more expressive. Several women requested follow-up meetings with the author; and several were successfully referred to therapists for individual treatment.

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Three of the participants approached the author weeks after the meeting to remark that various realizations had resulted from our discussion.

A consistent social work presence within the clinic setting provided access to both concrete and emotional support for these women. While many participants did take advantage of the support offered by the staff social workers, many more did not. The author's status as both "insider," and "outsider" in the clinic may have contributed to the eagerness with which so many women participated. My face was a familiar one, introductions were carried out by known clinic personnel, yet I was not installed in a permanent position in the clinic. For some women, this opportunity to talk without any commitment to an ongoing dialogue perhaps lessened the ambivalence they felt about confiding in someone. Additionally, the framing of their participation as a contribution, solicited in order to help others, may have been, for many of these women, a unique and welcome experience. The shunning of situations which might elicit pity from others, the avoidance of being a "burden" were recurrent themes in discussions with many of these women. Thus, the opportunity, in the context of this study, to speak about themselves and their concerns, not out of their own need but in order to assist others may have been both liberating and empowering.

Responses to specific components of the protocol were not

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particularly notable. Some women remarked after the meeting that they had found the TAT thought provoking; for others, on the contrary, this task seemed to provoke only insecurity about the "correctness" or "incorrectness" of their responses. Participants reactions to the semantic differentials were unremarkable. The format of this task was, perhaps, more familiar than were other components of the protocol. Concerns about the reactions of women to the Figure Outline task proved unfounded. While some women did note that the coloring reminded them of physical ailments that they did not ordinarily contemplate, none became upset by this. The task did not seem to compel a confrontation with unwelcome or threatening reflection as was evidenced by those women who did not color any part of the figure, stating that while they did have HIV, they were not currently experiencing any symptoms. For other participants the figure outline provided a welcome opportunity to share with an attentive listener each and every physical and mental complaint. Some women appeared to find the various tasks preceding the interview interesting, while others seemed impatient to reach the interview section of the protocol.

Recommendations and Conclusions

The present study illuminated some of the psychological ramifications for HIV infected women of their offsprings' serostatus. An apparent, though unanticipated, link between

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defense use among participants and the serostatus of their children was described. An HIV infected woman's perception of her own disease process appeared to be related to the serostatus of her child(ren), though again, not in the way which had been predicted. Evaluations of offspring by their mothers were, as well, linked to the children's serostatus; identification of mothers with their children appeared to be related to offspring serostatus based on interview data, though this was not demonstrated empirically. The present study revealed no impact of offspring serostatus on the level of affect maturity characteristic of mothers; the generally low level of affect maturity among all participants was noteworthy, however.

Both empirical data as well as clinical observations revealed striking differences in the experiences of women in the II and IU groups. The ways in which the experiences of the women in these groups diverged were not, however, consistent with hypothesized differences. The extraordinary requirements of caring for an HIV infected child, expected to be a disadvantage psychologically, seemed, on the contrary, to augment mothers' sense of purpose and well-being. The apparent idealization of such children by their mothers may also have contributed to the relatively positive experience these mothers had of themselves and their children. On the other hand, having a well child to "leave behind" highlighted both the illness of mothers in this situation as well as the

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impending "abandonment" of their children. Thus, contrary to predictions, this may have been experienced primarily as an emotional burden and indication of maternal failure.

Women in the II group were, by and large, able to use denial in moderation -- that is, to a degree which was helpful in sustaining hope without impairing other ego functions. The two exceptions to this were in the areas of their own health care and contraception; here, excessive denial use may have impeded rational decision making. Women in the IU group, on the other hand, seemed to run a particular risk of insufficient mobilization of denial. This was reflected in the pronounced negativity regarding their own health, their future health and the future in general.

Thus, findings from this study revealed some issues pertinent to work with HIV infected women. The apparent deficiency in adaptive defenses exhibited by women in the IU group is of particular concern given the expected increase in this population, (see introduction regarding recent findings indicating that the administration of ZDV during pregnancy reduces the rate of vertical HIV transmission from approximately 30% to 8%). It is also worrisome due to the recent research noted above which suggests a relationship between immune function and such factors as coping style, attitude, and depression (Fawzy, Fawzy, & Pasnau, 1991; Ickovicks & Rodin, 1992).

Findings from the present study suggest the possibility

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of a connection between the experience these (IU) women have of themselves as mothers and their apparent difficulty with defense mobilization. Empirical examination of this connection is highly recommended. Such research might include further comparisons of women in the IU and II groups through additional exploration of defenses, self-esteem, depression and guilt, as well as specific inquiry into the perceptions these women have of themselves as mothers.

Even without such empirical confirmation, however, the present study suggests the importance of particular sensitivity among clinicians to the possibility that HIV infected women with uninfected children may need assistance in bolstering their defenses. Such women may be at greater risk for despair than other HIV infected women. As well, attaining a feeling of having mothered "well" may be a pivotal component in the psychological well-being of women in this situation.

Findings from this study also suggest the need for clinicians to be particularly alert to the possibility that among HIV infected women with infected children denial may impair rational decision making with regard to the use of contraception and compliance with medical regimens. As well, women in this situation may suffer a crisis in hope upon the death or severe illness of their children. The eagerness with which so many women responded to recruitment efforts and the degree to which they seemed to benefit from the

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opportunity to speak about themselves contrasted sharply with the reluctance of many participants either to obtain support from the staff social workers at Bellevue or to follow through on referrals to other agencies. This disparity may, in part, relate to the determination to avoid "pity" described by so many participants. Many of the women who took part in the present research related histories of coping without much support from others and a determination to continue to do so. Encouragement to "seek help" might, by such women, be interpreted as confirmation of their own failure. "Help" may be resisted both out of a wish to avoid feeling like a "burden" as well as in an effort to sustain a belief in self-sufficiency. For many of the participants in the present study the loss of control over so much of life has been profound. Such women might find a therapy described as a means of gaining greater control, a learning opportunity, and in the case of group therapy, an opportunity to give as well as receive help more appealing than a therapy described as a place to go to "get help." Those women who expressed an initial reluctance to meet with this author generally found the assurance that they would discuss only what they felt comfortable discussing, answer only those questions they felt comfortable answering, and could decide at any time that they no longer wished to participate quite comforting; that is, in consenting to participate they would not relinquish control. Emphasis on the control which can be had _within_ the

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therapeutic context might also be helpful. A therapy which such women could "own" might even prove attractive to them.

Along with testing and describing readily measurable differences between the groups delineated, this study aimed, through its design, to provide qualitative data as well. It was hoped that such information would, aside from helping to elucidate the quantifiable data, itself be of use clinically. This combination of the measurable and the immeasurable, ensures, I hope, that the meaning of the material at hand will be understood for both its statistical as well as its emotional significance. Through the explication of some of the experiences encountered by the participants in this study -- along with the attendant hopes, fears, conflicts, and wishes -- attention was drawn to some of the themes and issues faced by many HIV infected women.

Along with the deep fear, sadness and anger expressed by many women who participated in this work, I witnessed astounding courage, a tenacious hold on life, and an unmistakable devotion to children and other loved ones. The extraordinary difficulties faced by these women make such positive qualities all the more remarkable. It is my hope that this work has adequately conveyed both these qualities as well as my deep respect for all of the women who shared their experiences with me so generously.

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APPENDIX A: CDC Classification System for HIV Infection

1. Adolescents and Adults*

The CD4+ T-lymphocyte is the primary target for HIV infection. The CD4+ T-lymphocyte coordinates a number of important immunologic functions, and a loss of these functions results in progressive impairment of the immune response. Studies have shown a strong association between the development of life-threatening opportunistic illnesses and the absolute number or percentage of CD4+ T-lymphocytes. As the number of CD4+ T-lymphocytes decreases, the risk and severity of opportunistic illnesses increase.

The revised CDC classification system for HIV-infected adolescents and adults categorizes persons on the basis of clinical conditions associated with HIV infection and CD4+ T-lymphocyte counts. The system is based on three ranges of CD4+ T-lymphocyte counts and three clinical categories and is represented by a matrix of nine mutually exclusive categories.

- **CD4+ T-Lymphocyte Categories**
  - Category 1: ≥500 cells/μL
  - Category 2: 200-499 cells/μL
  - Category 3: <200 cells/μL

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(APPENDIX A - CDC Classification System for HIV Infection)

- **Clinical Categories**

Category A

Category A consists of one or more of the conditions listed below in an adolescent or adult (≥13 years) with documented HIV infection. Conditions listed in Categories B and C must not have occurred.

- Asymptomatic HIV infection
- Persistent generalized lymphadenopathy
- Acute (primary) HIV infection with accompanying illness or history of acute HIV infection

Category B

Category B consists of symptomatic conditions in an HIV-infected adolescent or adult that are not included among conditions listed in clinical Category C and that meet at least one of the following criteria: a) the conditions are attributed to HIV infection or are indicative of a defect in cell-mediated immunity; or b) the conditions are considered by physicians to have a clinical course or to require management that is complicated by HIV infection.

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(APPENDIX A - CDC Classification System for HIV Infection)

Category C

Category C includes the clinical conditions listed in the AIDS surveillance case definition.

2. Children Under 13 Years of Age**

Summary of the Classification of HIV Infection in Children Under 13 Years of Age

Class P-0: Indeterminate Infection

Class P-1: Asymptomatic Infection

- Subclass A: Normal Immune Function
- Subclass B: Abnormal Immune Function
- Subclass C: Immune Function Not Tested

Class P-2: Symptomatic Infection

- Subclass A: Nonspecific Findings
- Subclass B: Progressive neurologic disease
- Subclass C: Lymphoid interstitial pneumonitis
- Subclass D: Secondary infectious diseases
  - Category D-1: Specified secondary infectious diseases listed in the CDC surveillance definition for AIDS
  - Category D-2: Recurrent serious bacterial infections
  - Category D-3: Other specified secondary infectious diseases

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(APPENDIX A - CDC Classification System for HIV Infection)

Subclass E: Secondary cancers

Category E-1 Specified secondary cancers listed in the CDC surveillance definition for AIDS

Category E-2 Other cancers possible secondary to HIV infection

Subclass F: Other diseases possibly due to HIV infection

* For additional detail please refer to the following: Centers for Disease Control (1992). 1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS among Adolescents and Adults. Morbidity and Mortality Weekly Report, 41(RR-17).

** For additional detail please refer to the following: Centers for Disease Control. (1987). Classification System for Human Immunodeficiency Virus (HIV) Infection in Children Under 13 Years of Age. Morbidity and Mortality Weekly Report, 36(15), 225-230.

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APPENDIX B: Demographics*

PARTIC #	GROUP	AGE	RACE	EDUCA	DRUGS	WORK	LIVING ARR	MODE TRAN	SINCE DIAG	S/A	CH SEX	CH AGE	SINCE DIAG CH	CH S/A
1	II	28	H		N	N	WO	S	6.00	A	M	4.00	4.00	A
2	II	30	H	12	Y	N	W	S	2.33	A	M	2.00	2.00	A
3	II	21	W	12	N	Y	W	S	1.00	A	F	0.75	0.75	S
4	II	24	H	14	N	N	W	S	1.00	A	M	5.00	1.00	S
5	II	29	B	14	N	N	W	S	5.00	S	F	4.00	3.75	A
6	II	36	B	14	Y	N	W	S	4.00	A	F	0.50	0.50	S
7	II	30	W	14	Y	N	W	S	5.00	A	F	1.17	1.17	S
8	II	47	H	12	Y	N	WO	S/N	1.25	S	M	9.00	0.75	A
9	II	22	H	12	N	N	W	S	3.00	A	F	3.00	2.75	A
10	II	25	W	10	Y	N	WO	S	3.00	S	M	0.50	0.50	S
11	IU	38	B	12	Y	N	WO	N	2.50	S	F,M	2.00,11.00	N/A	N/A
12	IU	25	B	12	Y	N	WO	S	2.00	S	F	2.00	N/A	N/A
13	IU	36	H	14	Y	N	WO	DK	2.50	A	F,M	2.00,9.00	N/A	N/A
14	IU	31	H	13	Y	N	W	S	5.00	S	M,M	5.00,7.00	N/A	N/A
15	IU	26	B	14	N	Y	W	S	3.66	A	M	4.00	N/A	N/A
16	IU	22	B	10	Y	N	WO	S	5.42	A	M	3.00	N/A	N/A
17	IU	37	B	12	Y	Y	WO	DK	1.25	A	F,M	1.25,2.50	N/A	N/A
18	IU	30	H	11	Y	N	W	S	4.66	S	M,M	4.00,5.00	N/A	N/A
19	IU	31	H	12	N	N	WO	S	2.00	A	F	3.00	N/A	N/A
20	IU	30	W	12	Y	N	W	N	1.00	A	M	0.17	N/A	N/A
21	IIU	42	H	9	Y	N	W	N	3.00	S	M,F	9.00,16.00	3.00	S
22	IIU	29	H	11	N	N	W	S	1.50	A	F,F	2.00,9.00	1.50	A
23	IIU	43	B		N	N	WO	S	6.00	S	F,F	9.00,23.00	4.00	S
24	IIU	32	B	13	Y	N	WO	S	2.50	A	M,F	0.67,1.50	0.66	A
25	IIU	29	H	11	Y	N	WO	S	3.00	A	F,M	2.00,10.00	2.00	S
26	IIU	32	B	13	Y	N	WO	DECL	0.33	S	M,F	1.25,7.00	0.33	S
27	IIU	31	B	12	Y	N	WO	S	1.50	A	F,M	4.00,2.00	1.50	A
28	IIU	30	B	12	Y	N	WO	S	0.50	S	M,F	0.92,9.00	0.50	S
29	IIU	36	B	13	Y	N	WO	S	0.75	S	M,M	1.50,10.00	1.00	S
30	IIU	38	B	9	Y	N	W	S	5.00	S	F,M	4.00,12.00	0.45	S
31	UU	37	H	9	Y	N	W	N/A	N/A	N/A	F,F	3.00,13.00	N/A	N/A
32	UU	24	B	11	Y	N	WO	N/A	N/A	N/A	M	0.75	N/A	N/A
33	UU	28	H	14	Y	N	WO	N/A	N/A	N/A	F	3.00	N/A	N/A
34	UU	26	B	12	N	Y	W	N/A	N/A	N/A	M	2.50	N/A	N/A
35	UU	26	H	13	N	Y	W	N/A	N/A	N/A	M,M	1.00,4.00	N/A	N/A
36	UU	34	B	12	Y	N	WO	N/A	N/A	N/A	M	0.75	N/A	N/A
37	UU	37	B	12	N	Y	WO	N/A	N/A	N/A	F,F	4.00,17.00	N/A	N/A
38	UU	20	H	12	N	N	W	N/A	N/A	N/A	F	1.00	N/A	N/A
39	UU	30	H	16	Y	N	W	N/A	N/A	N/A	M	3.00	N/A	N/A
40	UU	24	B	10	N	N	WO	N/A	N/A	N/A	M	4.00	N/A	N/A

* Notes for Appendix B:

Race: B = Black, H = Hispanic, W = White
Education: In years
Drugs: Y = Past use of heroin or cocaine
Work: Y = Employed at time of interview
Living: W = Living with at least one other adult
WO = Living without another adult
Mode of Transmission:
S = Sexual
N = Needles (from IV drug use)
DK = Don't know
DECL = Declined to answer
(In accordance with CDC guidelines, S/N responses are counted as N)
Since Diagnosis: presented in years
CH = Child
Since Diagnosis of Child: presented in years
S/A: Based on CDC criteria
S = Symptomatic
A = Asymptomatic

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APPENDIX C: Informed Consent (According to NYU Medical Center/Bellevue Hospital specifications)

NEW YORK UNIVERSITY MEDICAL CENTER
AND BELLEVUE HOSPITAL CENTER
INFORMED CONSENT TO PARTICIPATE IN RESEARCH

You are asked to participate in a research study. This form is designed to provide you with information that you should have about this study and to answer any of your questions.

TITLE OF RESEARCH STUDY: Health, Illness, and Motherhood

YOUR PARTICIPATION WILL INVOLVE THIS AMOUNT OF TIME: 1-2 Hours

WE EXPECT TO ENLIST THIS NUMBER OF VOLUNTEERS: 60

This research study includes procedures that may change the treatment your child would otherwise receive. We hope the knowledge gained will be of benefit to you. (May not be applicable to adult participants).

This research study includes procedures that may not give your child immediate benefits. It is hoped the knowledge gained will be of benefit to others in the future. (May not be applicable to adult participants).

This research study is planned to select your treatment by chance. It is not known if the treatment your child will receive will be of benefit. (May not be applicable to adult participants).

THE PURPOSE OF THIS RESEARCH IS: The purpose of this study is to learn more about how mothers feel about health and illness in themselves and in their children. We are interested in how mothers handle the many demands they face in taking care of their families and in taking care of themselves. As part of this study we will be trying to find out whether there are certain things that make it easier or more difficult for mothers to face these demands.

THE FOLLOWING PROCEDURES WILL BE INVOLVED: The study involves one visit that will last for about 90 minutes. The visit will take place during one of your child's regularly scheduled clinic appointments or at another time which is convenient for you. During the visit you will be asked questions about yourself, your child(ren), and any stresses you've been under lately. You will also be asked to fill out a few short questionnaires and complete a brief drawing task. Finally, you will be asked to look at some pictures and make up brief stories about what you see.

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You will be reimbursed $10.00 to cover any expenses (Lunch or transportation) associated with the visit.

As part of the study, we will need information about your health and the health of your child. Therefore, we will be contacting (APPENDIX C: Informed Consent)
primary care physicians. This information, as all information, will remain completely confidential. Everything that you talk about during the visit will be private. In order to protect your privacy, you will be assigned a random number and all information you share in the study will have only this number to identify it.
None of the documents which are produced as a result of this study will contain any identifying information in them.

None of the information you share will be given to either your or your child(ren)'s doctor. Your decision to participate in this study will in no way affect the medical care you and your child(ren) receive.

POTENTIAL RISKS OR DISCOMFORTS TO YOU ARE: While there are no known risks associated with any of the tasks we will ask you to complete in this study, there is a possibility that you may feel upset in talking about some issues related to the stress you are under, or your or your child's health.

THE POTENTIAL BENEFITS TO YOU OR TO OTHERS ARE: You might find that you like having the opportunity to express some of your feelings and concerns. You may also have questions about your child(ren)'s development or how you can most help your child develop. We will answer what questions you do have. Also, if you are finding that your problems are difficult to solve yourself we will try to help you find someone to address these problems with you.

Through your participation in this study you will be helping us to learn about the concerns mothers have about health matters and how they try to handle these concerns. You will also be helping us to find out the kinds of things for which mothers need most help and support.

If you agree to participate in this study you are free to change your mind at any time and stop participating. If you had started to participate and you would like us to destroy information we had already gotten, we would do so.

IF YOU DO NOT PARTICIPATE IN THE RESEARCH, YOU MAY RECEIVE THE FOLLOWING ALTERNATIVE TREATMENT: Your decision to participate in this research will not affect the treatment you receive at Bellevue Hospital.

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(APPENDIX C: Informed Consent)

________________________________/________________________________

Signature of Parent (Subject) or Legal Rep.* and Date

Signature of Investigator and Date

____

Print Name of Legal Representative

*If a subject is unable to provide informed consent, this agreement must be signed by a parent or other legal representative. For children between the ages of 12 and 17, their signature is generally required in addition to that of the parent or legal representative.

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APPENDIX D: Measures

1. Semantic Differentials

ME

Beautiful	___	___	___	___	___	___	___ Ugly
Selfish	___	___	___	___	___	___	___ Unselfish
Happy	___	___	___	___	___	___	___ Sad
Weak	___	___	___	___	___	___	___ Strong
Innocent	___	___	___	___	___	___	___ Guilty
Useful	___	___	___	___	___	___	___ Useless
Healthy	___	___	___	___	___	___	___ Sick
Hopeless	___	___	___	___	___	___	___ Hopeful
Worthless	___	___	___	___	___	___	___ Valuable
Unloving	___	___	___	___	___	___	___ Loving
Productive	___	___	___	___	___	___	___ Destructive
Large	___	___	___	___	___	___	___ Small
Light	___	___	___	___	___	___	___ Heavy
Bad	___	___	___	___	___	___	___ Good
Kind	___	___	___	___	___	___	___ Cruel
Dirty	___	___	___	___	___	___	___ Clean

Participant #:

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(APPENDIX D: Measures)

1. Semantic Differentials

THE FUTURE

Nice	___	___	___	___	___	___	___	Awful
Short	___	___	___	___	___	___	___	Long
Unfair	___	___	___	___	___	___	___	Fair
Worthless	___	___	___	___	___	___	___	Valuable
Meaningful	___	___	___	___	___	___	___	Meaningless
Useless	___	___	___	___	___	___	___	Useful
Healthy	___	___	___	___	___	___	___	Sick
Hopeless	___	___	___	___	___	___	___	Hopeful
Full	___	___	___	___	___	___	___	Empty
Sad	___	___	___	___	___	___	___	Happy
Productive	___	___	___	___	___	___	___	Destructive
Loving	___	___	___	___	___	___	___	Unloving
Kind	___	___	___	___	___	___	___	Cruel
Bad	___	___	___	___	___	___	___	Good

Participant #:

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(APPENDIX D: Measures)

1. Semantic Differentials

MY BODY

Strong	___	___	___	___	___	___	___	Weak
Good	___	___	___	___	___	___	___	Bad
Worthless	___	___	___	___	___	___	___	Valuable
Productive	___	___	___	___	___	___	___	Destructive
Useless	___	___	___	___	___	___	___	Useful
Sick	___	___	___	___	___	___	___	Healthy
Hopeless	___	___	___	___	___	___	___	Hopeful
Full	___	___	___	___	___	___	___	Empty
Dirty	___	___	___	___	___	___	___	Clean
Beautiful	___	___	___	___	___	___	___	Ugly
Light	___	___	___	___	___	___	___	Heavy
Painful	___	___	___	___	___	___	___	Painless
Kind	___	___	___	___	___	___	___	Cruel
Polluted	___	___	___	___	___	___	___	Pure
Young	___	___	___	___	___	___	___	Old
Small	___	___	___	___	___	___	___	Large

Participant #:

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(APPENDIX D: Measures)

1. Semantic Differentials

SICKNESS

Fast	___	___	___	___	___	___	___	Slow
Small	___	___	___	___	___	___	___	Large
Kind	___	___	___	___	___	___	___	Cruel
Ugly	___	___	___	___	___	___	___	Beautiful
Clean	___	___	___	___	___	___	___	Dirty
Passive	___	___	___	___	___	___	___	Active
Light	___	___	___	___	___	___	___	Heavy
Hopeless	___	___	___	___	___	___	___	Hopeful
Good	___	___	___	___	___	___	___	Bad
Near	___	___	___	___	___	___	___	Far
Strong	___	___	___	___	___	___	___	Weak
Sharp	___	___	___	___	___	___	___	Dull
Nothing	___	___	___	___	___	___	___	All

Participant #:

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(APPENDIX D: Measures)

1. Semantic Differentials

MY CHILD

Beautiful	___	___	___	___	___	___	___	Ugly
Selfish	___	___	___	___	___	___	___	Unselfish
Happy	___	___	___	___	___	___	___	Sad
Weak	___	___	___	___	___	___	___	Strong
Innocent	___	___	___	___	___	___	___	Guilty
Useful	___	___	___	___	___	___	___	Useless
Healthy	___	___	___	___	___	___	___	Sick
Hopeless	___	___	___	___	___	___	___	Hopeful
Worthless	___	___	___	___	___	___	___	Valuable
Unloving	___	___	___	___	___	___	___	Loving
Productive	___	___	___	___	___	___	___	Destructive
Large	___	___	___	___	___	___	___	Small
Light	___	___	___	___	___	___	___	Heavy
Bad	___	___	___	___	___	___	___	Good
Kind	___	___	___	___	___	___	___	Cruel
Dirty	___	___	___	___	___	___	___	Clean

Participant #:

Child #:

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(APPENDIX D: Measures)

2. Figure Outline

Upon presentation of figure outlines to participants:
"Please color in the areas (if any) that you feel have been touched by or affected by sickness. Where is the sickness? - color in the parts of your body where it is located."
Clarify if necessary that areas which are presently hurting are not necessarily those that which should be colored, rather, the areas to be colored are those inside of the body that participants think of more generally as where the sickness has, over time, affected them.

" The different colors are to show how severely/badly these areas are affected or how much sickness there is in a particular place - how strong the sickness is:

- Use red to show areas that are extremely affected - where the disease most affects you - where it is very strong.
- Use orange for areas that are affected a medium amount - where there is a lot of disease - where it's moderately strong.
- Use yellow for areas that are only affected a little - where there is only a little disease - where it's there but it's weak."

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(APPENDIX D: Measures)

2. Figure Outline

To be given to physicians along with figure outlines and pencils:

By coloring in the accompanying figure outlines, please indicate the areas of your patient's body which have been affected by illness. The different colors are to be used to represent the severity with which each region has been affected.

- If a manifestation of disease has been cause for hospitalization, has led to permanent changes in functioning, or continuous and severe discomfort, this would indicate a rating of severe effect (RED).

- Symptoms which cause periodic and significant discomfort would be rated as having quite an effect (ORANGE).

- Areas which have been affected but in ways that cause minimal inconvenience, discomfort, or symptoms that are rapidly curtailed by medication would warrant a mild effect rating (YELLOW).

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(APPENDIX D: Measures)

2. Figure Outline

Participant #:

MD/PA

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(APPENDIX D: Measures)

3. Interview

[Note how upset did the participant seem during the drawing task? What kind of recovery did she make?]

What was it like to do the drawing? What kinds of feelings did it raise? thoughts? fantasies?

Some of the questions I'm going to be asking may feel very personal. I want to remind you that all of the information you share with me is totally confidential - your name will not be associated with any of this information. [state on recording participant # and, at relevant time, child's #].

BASIC INFORMATION

Age __________

Race/Ethnicity ______________

Marital Status _________________

Current Housing - permanent? shelter? ever were wo/ a home?

Household Composition:

Occupation/Work history:

Education:

Income - Amount_______________ Is it enough?_____________

Drug history - When Began? ____________ What___________

Current Usage? ___________________________

Religion - Growing up ___________________________________

Currently ___________________________________

Afterlife beliefs

Participant #:

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(APPENDIX D: Measures)

LOSSES

Ever lost someone or something really impt to you? (who/what/when?)

STRESSES

EG: Health? $? Housing? Violence?

What do you worry about most?

Any major changes recently?

SOCIAL SUPPORT

Who do you turn to for help? To talk ? For $? For babysitting?

Who turns to you??

Social life - What do? With Whom?

Restrictions?

CHILD(REN)/MOTHERING (If more than one child, ask questions first about one, then the other.)

Pregnancy experience - Planned?

Physically?

Emotionally?

Compared with Expectations?

Delivery experience -

Physically?

Emotionally?

Compared with Expectations?

Participant #:
Child #:

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(APPENDIX D: Measures)

Describe child

Look like?

Act like?

What like/enjoy most/least about him/her.

Does she/he resemble you? how so? how not? (EG: Appearance/Behavior/Tastes/Moods)

What's most fun/ gives you most pleasure in being a parent?

What's hardest about it?

What do you especially like to do with child?

What do you least like to do with child?

When do you feel closest to your child?

When do you feel you understand your child the best?/least?

When do you feel most distant from your child?

When you worry abt your child, what do you find yourself worrying most about?

Have you ever been separated from your child? How long? What like?
(EG: Foster care? Hospital? Vacations?)

Future hopes/fears - how do you imagine your child five years from now?
(How about yourself?)

REPRODUCTIVE HISTORY (& Wishes/ Intentions)

Other pregnancies? When? planned? wanted?

Miscarriages? When? Feelings?

Abortions? When? Feelings?

Attitude toward abortion? When Ok? Ever not?

Participant #:
Child #:

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How often would you say you have sex? (avg in last few months).

Practice birth control? All the time?

Have you attempted to get pregnant in the last few months?

Do you think about having more children? Do you want to? Plan to? When?

Hopes/Expectations for that child... How do you imagine that child?

BASIC HIV KNOWLEDGE

What are the ways that someone could get HIV? Adult?/Child?

What happens once someone gets it? Child? Adult?

[Only if participant has herself volunteered that she is HIV infected]

How explain how you got it?

How child got it?

When diagnosed?

Who told you?

What was that like?

Who have you told? Their reactions?

When child diagnosed?

Who told you?

What was that like?

Who have you told? Their reactions?

Participant #:
Child #:

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(APPENDIX D: Measures)

That's all we need to do ... Any questions/ concerns - anything we touched on that you'd like to talk more about? Thank you.

Pd $10 _____
Date: _______________

COMMENTS:

Participant #:

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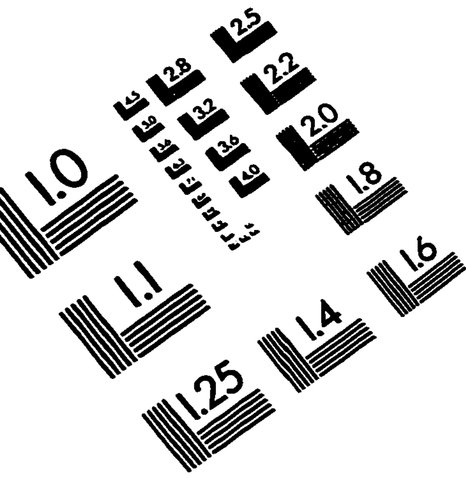
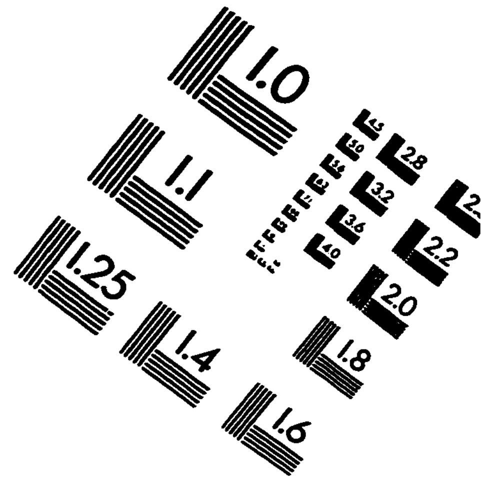
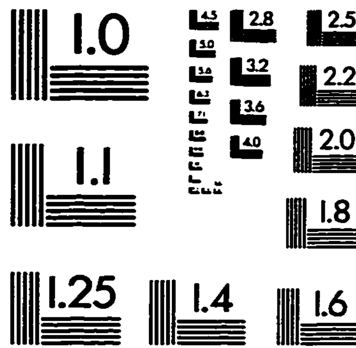
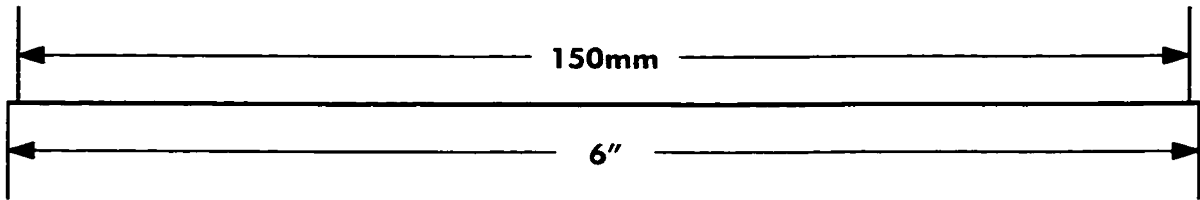
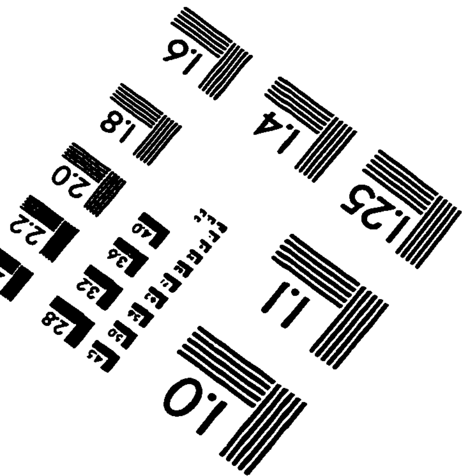
IMAGE EVALUATION TEST TARGET (QA-3)

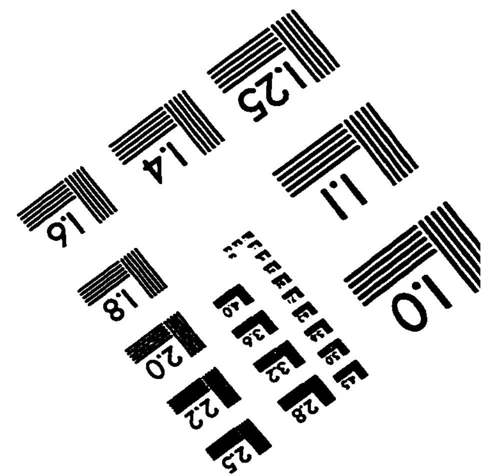












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