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The experience of the HIV-positive mother with an HIV-positive child

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THE EXPERIENCE OF THE HIV-POSITIVE MOTHER WITH AN HIV-POSITIVE CHILD: A DESCRIPTIVE STUDY

by

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ABSTRACT

THE EXPERIENCE OF THE HIV-POSITIVE MOTHER WITH AN HIV-POSITIVE CHILD: A DESCRIPTIVE ANALYSIS

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There is little published research that directly addresses the impact of HIV infection on the infected mother-child dyad. The noncategorical approach to families of children with chronic, life-threatening illness provides a framework for studying pediatric HIV families. However, because of the unique aspects of pediatric HIV infection, research must go beyond identification of commonalities with other chronic childhood diseases and determine the specific impact of HIV infection. The purpose of this investigation was to discover the experience of the HIV-positive mother who also has an HIV-positive child.

The sample consisted of twenty HIV-positive mothers with at least one HIV-positive child recruited from northern California. Mothers' ages ranged from 27 to 44 years old; children's ages ranged from 5 months to 8 years old. The majority were African American (65%), followed by Caucasian (20%) and Hispanic (15%). Five families had other children at home.

The research design was exploratory-descriptive. Data was obtained through semi-structured interviews using open-ended questions. Data analysis applied the process of latent content analysis.

The data revealed contextual and salient dimensions of the mothers' experiences associated with uncertainty, stigmatization, finding out the diagnosis, effect on family, blame, feeling helpless, hope, and disclosure. Strategies used by the mothers to manage their illness and emotional distress were also identified. The findings support the noncategorical aspects of HIV infection as a chronic illness as well as identify categorical aspects of HIV infection when both mother and child are infected.

Signed Ida M. Martinson
Ida M. Martinson, PhD
Dissertation Chair

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CHAPTER ONE

INTRODUCTION

In the United States, women comprise the fastest growing population of acquired immunodeficiency syndrome (AIDS) cases. By mid-1996, the reported number of U.S. AIDS cases among women was 78,654, up from 51,235 in 1991 (CDC, 1996). African American women account for 55% of all female adult/adolescent AIDS cases with 23.7% for White and 20.3% for Hispanic women. Human immunodeficiency virus infection (HIV) among childbearing women between ages 13 and 49 years represents 93% of all U.S. female HIV infection cases (CDC, 1996).

Mother-to-child (perinatal) transmission of human immunodeficiency virus (HIV) accounts for 6,586 (90%) pediatric AIDS cases (CDC, 1996). Although no data about mothers is available, general information may be inferred from the statistics on perinatally-infected children (CDC, 1996). For example, 57.6% of these children are African Americans, 23% Hispanics, and 18% White. Nearly 60% have mothers involved with injection drug use or sexual contact with an injection drug user. For almost 25% of the mothers, no risk factor for HIV was reported. However, of all women with AIDS (not only mothers) who initially reported unknown risk, 93% were ultimately found to be infected through sexual contact or injection drug use. Therefore, it is likely that maternal risk factors associated with sexual behavior or drugs are actually greater than reported.

There are 6,586 pediatric AIDS cases (CDC, 1996) and it is estimated that there are 15,000-20,000 more children with HIV infection (Pizzo, 1995). With advancements in diagnosis, treatment, and disease management, both adults and children with HIV infection and AIDS live longer, although they may not ultimately survive (Oxtoby, 1994). Their increased survival has placed HIV infection among the major life-threatening chronic illnesses being managed by families.

Many families have had (or will have) the experience of caring for a chronically ill family member due to changing health care practices and longer life spans. It is likely that HIV-infected mother and child family will demonstrate some of the same characteristics as other families with chronic illnesses. However, it is important to recognize the unique factors of HIV disease that may affect these families. First, disease causation is known, with vertical transmission from infected mothers accounting for 99% of all new pediatric infections. Second, there is disproportionate representation of HIV disease among children of color (National Pediatric Resource Center, 1992). Third, HIV infection is strongly associated with stigmatized lifestyles related to sexual behaviors and drug use. Finally, in families with an HIV-positive mother with an HIV-positive child, the infected mothers are also likely to be the primary caregiver, responsible for managing their own health needs as well as their child's.

These data suggest that HIV is likely to affect the mother with an infected child across all levels of relationships, both intrafamilial (children and partner may also be affected) and extrafamilial (stigmatization related to ethnicity, socioeconomic status, drug use, or sexual behavior). However, there is little research published on the infected mother in the pediatric HIV family. A review of the literature revealed a substantial amount of literature on the noncategorical features of chronic illness likely to apply to the HIV family (Pless & Perrin, 1985; Rolland, 1984; Sabbeth, 1984). Most families with chronic illness face major issues related to: (a) the trajectory of the illness; (b) self-identity and development; (c) the quality of life; (d) stress and coping; (e) grief, loss, and sorrow; (f) uncertainty; and (g) stigmatization.

The existing body of literature on the HIV-infected mother and her infected child is limited both in the depth and scope of its exploration. While some aspects of HIV disease may be attributed to the chronic illness nature of the disease, it is not yet known to what extent they are similar or different. For example, one unpublished study (cited in Cohen, 1994) used a standardized measure to determine parental depression in parents of HIV-infected children. Nearly 25% of the parents reported moderate to severe depression; they also reported more depressive symptoms than parents of cancer children. What the study did not reveal was the *why*, *when*, and *under what circumstances* that are necessary to understand depression in the pediatric AIDS parent.

The scope of the existing literature is limited as well. There is little published literature that directly addresses the impact of HIV infection on the infected mother or the infected child. Descriptions have been limited to few concepts (stress, coping, anxiety, depression, adaptation). The majority of measurement tools to describe these concepts have not been trialed on this population, so the findings reported may be flawed. The available research literature does not offer sufficient data to construct a comprehensive view of the mother's perceived experience within the context of her environment.

Research is needed to identify the contextual variables that influence the life of infected mothers, their relative weight, the relationships among them, and the role that they play (e.g. related to decision-making, illness management, disclosure). Further, any research to explore the experience of HIV-infected mothers and children must also consider the influence of the many levels of variables that are known as well as facilitate the discovery of those that are not known.

The research focus of this study was the HIV-infected mother who also has a child with HIV infection. The maternal experience and associated events such as the physical experiences of providing care and coping and the emotional experiences related to blame, feeling helpless, hope, and disclosure constituted the essence of this study. The mothers' experiences, as told in their own words, were identified, discussed, and analyzed by this researcher.

The purpose of this study was to explore and describe the experience of the HIV-infected mother with an HIV-infected child and to provide an analysis of the central themes which emerged during the process of data collection. The term *experience* encompasses the salient behaviors, events, beliefs, attitudes, structures, and occurring processes as perceived by the mother. Specifically, this study sought to answer the essential question: How do HIV-infected mothers who have an HIV-infected child perceive their experience?

Significance of the Study

The knowledge generated in this study provided a picture of the infected mother as situated in diverse, but interconnected, relationships at multiple levels of interaction. The data allowed the HIV-infected mother with an infected child to be examined in two ways: (a) singularly, in identifying individual characteristics on a case-by-case basis and (b) collectively, in viewing the mothers as a group.

When applied on a case-by-case basis, the findings provide a narrow, singular perspective of how HIV impacts each infected mother across all levels of her environment and how her characteristics influence her response to HIV infection. These specific characteristics or relationships may be used to guide further research. The findings also provide a picture of these case studies as a group. Collective issues of the group, such as their greatest needs, illness management priorities, and opportunities and risks, have been identified as well.

In addition, the information acquired has the potential to guide future research as well as direct intervention efforts. When applied to a single infected mother-child situation, the findings allow the clinician and the mother to identify areas that present opportunities or risks. Because a problem in any member of a family affects all other members, the findings can help determine the impact of the problem and thereby direct the intervention. When applied collectively to a group of infected mothers within a community, the findings can identify areas the mothers perceive as their greatest needs or risks. Consequently, community programs can be developed that are meaningful and resources may be provided that are useful to the infected mother and child.

CHAPTER TWO

REVIEW OF THE LITERATURE

Any serious, life-threatening illness affects the function of the entire family as well as the ill member. Because of the high incidence of vertical transmission of HIV from mother-to-child, families must deal not only with infection in the child but also in the mother and often in the father and siblings. While problems of families with a member with AIDS have been investigated, the experience of the HIV-positive mother with an HIV-positive child as a family has not been as fully explored.

This chapter presents a review of the existing body of literature that identifies potential dimensions of the experience of the HIV-infection mother with her infected child. However, there is a paucity of published research targeting HIV/AIDS families, particularly the experiences of HIV-infected mothers. Therefore, identification of potential concerns related to this group is heavily reliant on case reports. The literature is presented in three major research areas: (1) HIV-positive women; (2) HIV/AIDS families; and (3) HIV-positive mother-HIV-positive child families.

HIV-positive Women: Selected Research

There is much discussion about the issues for HIV-positive families and HIV-positive women in an attempt to provide direction for development of interventions. Issues and recommendations for care of HIV-positive mothers and their infected children have been proposed, oftentimes without supporting research. Further, maternal issues are usually researched as a subcategory of HIV-infected women or HIV/AIDS families instead of the primary focus of the research. Study descriptions summarizing the purpose, theoretical framework, design, sample selection, analytic technique, and major findings are provided in Appendix A: HIV-positive Women: Selected Research.

Weiner (1991) presents a historical and personal psychosocial perspective of HIV and women. She contends that scant attention has been paid to women in clinical practice or research. Issues have revolved around women as "vectors of transmission to men and children" rather than as "victims of transmission" (p.376). Little attention has been paid to the mother's predicament or her quality of life.

Based on her experiences with HIV clients, Weiner believes that the infected women grieve every day for their multiple losses: their health, hopes and dreams for the future, desirability, the unborn children they wanted, their financial security, and their friends, spouses, and children who have already died. They may be unable to express their sense (or fear) of multiple loss due to the stigma associated with HIV. They may already be alienated from traditional sources of support if they use drugs, thus intensifying their isolation. Wiener describes their experience as *silent grieving*.

Suffet and Lifshitz (1991) interviewed women addicts about their day-to-day struggles. Their AIDS-related responses became the basis for the descriptive categories related to: (a) fear, (b) risk assessment and reduction, and (c) antibody testing. The fear the women felt was grounded in reality. Almost everyone knew someone who had died of AIDS: " 'A friend of mine, he died of AIDS. My brother has ARC (AIDS-related complex). I may have ARC. My sister...has ARC also. I just got tested.' "(p. 62). All expressed fear for themselves or their children: " 'I've thought of [getting AIDS] for a long time...I was always so clean and careful...I hope I was' " and " 'I'm not ready to die.

I'm scared to death of it.' " (p. 62).

Injection drug use was the key risk factor for all the women in the sample. Because they no longer shared needles, had stopped injection drug use, or had never shared needles, they assessed their HIV risk by whether sexual partners were current or former injection drug users. When asked how they changed their behavior because of AIDS, most mentioned sexual behavior but most did not mention drug use. Risk reduction was related to changing their sexual behaviors rather than changing their drug use.

The decision to be HIV tested was difficult for some women. By not testing, the women avoided facing the uncertainties of a positive diagnosis: whether or when they will develop AIDS; when and how they will die. Having children was not a predictor of the mothers' willingness to be tested. Some mothers were so overwhelmed with the possibility of having infected their children, they avoided testing: " 'It's not that I don't want to [get tested]...I get scared. If I have it, my kids have it, too' " (p.72). Avoidance, even at the cost of not receiving treatment, allowed the mothers to hope and to maintain a semblance of normal life.

Hutchinson and Kurth (1991) investigated HIV-positive women and their reproductive decision-making. Eleven participants who had learned of their HIV status while pregnant (24 weeks gestation) were interviewed. The women were asked to identify those factors that influenced their reproductive decision; that is to continue or end their pregnancy. Factors identified by the women for carrying to term were a personal morality; desire for the child; religious faith, the advanced state of their pregnancy; and prior experience with having another child serorevert. Factors identified that influenced their decision to end their pregnancy included: desire to avoid stigma for child; directive counseling; fear of labor/delivery; fear of inability to care for the child; lack of adoption options; and their prior experience with waiting to see if their child seroreverted.

Coping strategies of the mother in decision-making were using their faith systems and practicing positive thinking or keeping an optimistic outlook. The implications of the results were directed at developing counseling efforts to assist in their decision-making process. Recommendations included encompassing grief processing as part of counseling, increasing awareness of caregivers' biases and assumptions, adapting facilities to meet the women's needs, and linking adult and pediatric HIV-related services.

Frank, Blundo, and Brabant (1995) explored the financial, physical, and emotional needs of 32 HIV-infected women living in southern Louisiana. They developed a three part questionnaire distributed at agencies and clinics listed in an HIV/AIDS Services Directory. The instrument assessed general needs (yes/no response), their immediacy and degree of need (Likert; always to never), and explored feeling sad, good, angry, scared, and helpless (six open-ended statements).

The most surprising findings were that subgroups' psychosocial considerations differed so little from each other. A majority of all the women needed financial help for health insurance and medicines. More than one-third needed transportation, support group access, and spiritual guidance. However, minority women were less than likely to attend support groups. Women with children were not likely to have greater financial need than those without children.

Another interesting finding was that disease progression does not necessarily result in greater financial or emotional needs. Those with T-cell counts >200cells/μ reported needs for financial assistance, health insurance, spiritual support, or legal assistance. Women with T-cells >500 cells/μ reported the need for support groups. The researchers suggest that those women with AIDS (T-cells <200cells/μ) may have more resources available to them.

The HIV-positive women identified children as an important factor in their emotional state, strongly identified with feelings of helplessness and anger. HIV/AIDS issues were more likely to be sources of anger for women >30 years old and for whites as well. HIV/AIDS issues were also the greatest source of feeling helpless for non-whites.

Moneyham, Seals, Demi, Sowell, Cohen, & Guillory (1996) explored issues of disclosure for HIV-infected women. Content analysis was used to code the data gathered from focus group sessions. Descriptions of disclosure revealed an evaluative process involving an analysis of potential risks and benefits in disclosing. Three themes were identified: (1) discrimination; (2) confidentiality; and (3) the context of disclosure. Further, women expressed concerns about the perceived impact of nondisclosure. Nondisclosure affected the resources and health care services as well as increasing isolation and loneliness. The women felt they had no supportive environment for disclosure, fearing negative responses from others.

From this same sample, Moneyham et al. (1996a) published findings related to the women's perceptions of stigmatization due to their HIV infection. As in their previous study, the researchers used content analysis to focus group data and identified four perceptions of the types of stigma perceived by the HIV-positive women: (a) distancing,

(b) overgeneralization of stereotypes, (c) social discomfort, and (d) pity.

Distancing was the perception that others desired to maintain a physical distance from those with HIV, likening their experience to being treated like “lepers” (p.164). Distancing was experienced in interactions with close associates as well as health care providers. *Overgeneralization of stereotypes* was the perception of others that presumed an association with HIV infection and stigmatized lifestyles, such as drug use or promiscuous sexual behaviors. *Social discomfort* was perceived to have occurred when people stated they were not uncomfortable with the HIV-infected individual, but acted otherwise. *Pity* was perceived by respondents when others either felt sorry for them or focused on them as dying. The respondents felt such pity to be stigmatizing because, as the recipient of the pity, it reinforced the perception of them as being different.

Their experience with stigmatization impacted their decisions to disclose their illness, fearing negative reactions from others. They chose to be selective in whom they confided and health care providers were often not among those. They reported the consequences of their secrecy as feeling isolated and lonely.

The relationship between time of diagnosis and entry into health care by HIV-positive women was investigated by Ickovics, Forsyth, Ethier, Harris, and Rodin (1996). Structured interviews were held with 48 HIV-positive women. Delayed entry into health care was defined as being more than three months from time of diagnosis and entry into care. Analysis included influence of race, social class, HIV risk behaviors, and health status.

Of this sample, 48% were considered to have delayed entry into care, with a mean delay of 17.6 months. Nearly three-fourths who delayed had fewer than 500 CD4 cells/mm^3. generally the point at which clinical intervention is indicated. However, there were no differences by the demographic and health variables listed above between those who delayed and those who did not.

A significant as well as interesting finding was that the timing of the diagnosis was the most important variable associated with a delayed entry into care. That is, those who were diagnosed during pregnancy were four times more likely to delay entry into care. Of this group, women with low SES and those of color were more likely to delay. However, the authors acknowledge that this was not statistically significant likely due to the small sample size and large standard error. There was no difference in delayed entry based on mode of maternal transmission (injection drug use versus heterosexual transmission).

HIV/AIDS Families: Selected Research Literature

The following review of HIV/AIDS families is examined in two parts: non-pediatric and pediatric families. Non-pediatric studies were selected when the subjects were mothers or caregivers of adult HIV-positive persons. Pediatric studies were selected when the subjects were children with HIV infection (less than 13 years old) or their families. Study descriptions summarizing the purpose, theoretical framework, design, sample selection, analysis, and major findings are provided in Appendix B: HIV/AIDS Families: Non-pediatric (Part I) and Pediatric (Part II). When a study is the preliminary findings of a larger study, data for both are included and reported as Preliminary Findings and Major Study.

Non-pediatric HIV/AIDS Families: AIDS Family Caregivers

In 1988, Trice interviewed 43 mothers to explore the relationship between their reported caregiving experience and the onset of primary symptoms associated with Post-traumatic Stress Disorder (PTSD). Two groups were selected for comparison: mothers who had directly cared for adult sons who died of AIDS and mothers who did not. Data was collected about the extent of care provided, attitudes towards their involvement in care, and the presence and onset of primary symptoms of PTSD.

Caregiving mothers were generally older than the noncaregiving group. Religious preference, employment, marital status, education, and race did not differentiate the two groups. The study findings, reported in Table 1, indicate that mothers who spent extended time as caregivers reported more PTSD-like symptoms than the noncaregiver group. Eighty-four percent of caregiving mothers reported three or more symptoms while only 8% of noncaregiving mothers reported that many symptoms. Most of the caregiving mothers (89%) agreed with the statement, " 'I feel so angry with the government and health care system for failing my son sometimes that I can barely control myself' " (p.657) compared to 21% of the noncaregiving group. Despite the negative impact, all mothers in the caregiver group reported they would repeat the experience.

While this study suggests that AIDS caregivers may experience negative effects to their health and lifestyle, its results must be interpreted with caution for several reasons. First, the method of data collection is not clear. The author does not provide the instrument nor indicate whether a survey or semistructured interview was used. However, it is clear that the PTSD categories were based on Blank's work with Vietnam veterans (cited in Trice). Second, the method of data analysis is not discussed. Thus, it is unclear whether an inductive or deductive approach was used. Third, no baseline measurement is provided for the PTSD symptoms as pre-existing conditions. Therefore, before an association between symptoms and AIDS caregiving can be made, it must be determined whether the symptoms are new or a pre-existing condition.

Table 1

PTSD-like Symptoms Reported by Caregiving and Noncaregiving Mothers (Trice, 1988)

	Mothers	
PTSD Symptoms	Caregivers (%)	Noncaregivers (%)
Night terrors	53	8
Panic attacks	42	29
Divorce/separation	37	13
Job change (not associated with length of caregiving)	32	8
Uncharacteristic violence	26	13
Psychosomatic disorders:		
migraines	21	13
hypertension	34	25

However, this study does provide valuable information about the caregiving experience of these mothers. That is, while both groups of mothers reported common PTSD-like symptomatology, the AIDS caregiving mothers attributed their symptoms or problems specifically to their caregiving experience.

Brown and Powell-Cope (1991) explored the experience of family members caring for persons with AIDS (PWAs) at home. The family caregiver was identified as the family of origin or the family of choice. The 53 HIV/AIDS family caregivers consisted of: (a) friends and former lovers, (b) partners in gay or heterosexual relationships, (c) parents of both adult and minor children, (d) siblings, and (e) other family of origin. Subjects were mostly gay or bisexual Caucasians with few caregivers of color.

Semistructured interviews guided the data collection. Grounded theory provided the methodological basis for data generation and its analysis. A substantive theory of AIDS family caregiving evolved from the data with the basic social-psychological problem of *uncertainty*, the core category of *transitions through uncertainty*, and five subcategories; *illness management; living with loss and dying; renegotiating the relationship; going public;* and *containing the spread of HIV.* Uncertainty pervaded this period of transition for the family, varying in intensity and content, but never totally disappearing.

In the subcategory, *managing and being managed by the illness*, uncertainty for caregivers emphasized that AIDS was poorly understood in its clinical presentation, meaning of symptoms and illness behaviors, treatment options, and effectiveness of caregiving. Caregivers felt overwhelmed by their continual feelings of "never being able to do enough" and being "24 hours a day on call" (p. 342). *Living with loss and dying* reflected three major sources of uncertainty for the caregiver: whether to remain hopeful, not knowing which illness or opportunistic infection heralds death, and when death would occur. In *renegotiating the relationship* with the PWA, the caregivers questioned their own commitment to caregiving, identified the PWA's caregiving expectations of them, and developed appropriate strategies to address the interpersonal stress of caring for someone who is dying.

Going public centered on the inability to predict other's responses to providing care for a PWA. Consequently, disclosure became carefully orchestrated by carefully determining who to tell and the type of information to be given. In *containing the spread of HIV*, uncertainty is reflected in the general fear surrounding transmission and their own lack of confidence in the current preventive recommendations. Uncertainty, pervasive throughout the experience, related to issues of loss and dying, interpersonal relationships, contagion, and disclosure.

This study provides a theoretical perspective on caregiving as a transitional period with the pervasiveness of uncertainty for those who care for PWAs. Uncertainty is an important dimension of HIV caregiving, not only related to the spectrum of illness itself, but to issues of loss and dying, interpersonal relationships, contagion, and illness disclosure.

Brown and Powell-Cope (1993) reviewed their 1991 study and explored their subcategory of *living with loss and dying*. Grounded theory methodology guided the analysis of this 1991 data. The category, *living with loss and dying*, was defined as the process of revising one's plan for living based on the possible and/or likely death of a loved one. This category was further dimensionalized by experiences that family members associated with their caregiving: *facing loss* and *transformed time*.

For the study participants, the experience of *facing loss* was confrontation with the reality of eventual death of the PWA, realization of this loss in their lives, and the beginning of acceptance. They reported the most painful and consuming aspect of living with loss was facing the death of the loved one. Caregivers reported multiple losses: dreams for the future, personal freedoms, previous lifestyles and relationships. They often wanted to discuss their feelings with the PWAs, but they feared that such discussion might depress the PWA or convey that they had given up hope. Thus, such attempts were awkward and painful.

Their second subcategory, *transformed time*, was experienced within the contexts of clock time and calendar time. Differences between days/weekends/weekends, their sense of clock time, seemed to vanish as the PWA required increasing daily care. Their sense of calendar time shifted from the previous assumption that the care giver-PWA relationship would last for many years to the current reality of the limited time left. Caregivers also focused on transformed time from past and future perspectives. While letting go of the previous life sometimes occurred gradually for some, others felt intense emotions about a life unjustly taken away. Caregivers felt consumed by caregiving and day-to-day living, postponing short- and long-term plans, putting their futures on hold.

Brown and Powell-Cope suggested that by shifting their sense of time, caregivers seemed to develop a clear focus for their lives, balancing immediate priorities with time for contemplation and reflection. Caregivers who were also HIV-positive focused on existential and spiritual concerns as they faced their own future illness and death.

The reports by Brown and Powell-Cope provide information about the caregiving experience across groups while the report by Trice provides information about mothers of infected adult children. These studies not only identify shared characteristics among their sample, they also introduce questions about the influence of the HIV status of the caregiver on the caregiving experience. In the Trice study, for example, the question is raised of how the caregiver being HIV-positive influences the PTSD symptoms associated with caring for her dying child. The Brown and Powell-Cope studies raises the question of whether the HIV-positive mother would construct her caregiving experience along similar themes, but also whether guilt, rather than uncertainty, might be the pervasive theme of her experience.

HIV/AIDS Pediatric Families

Sherwen, Barros, and Westervelt (1990) developed a nursing model to assess strengths and identify stressors in poor families with perinatally-transmitted HIV infection. They described these families as *disadvantaged* which they defined as groups who have been difficult to reach or do not respond to conventional outreach methods, such as poor, drug-using, or inner city populations of color. Their model presents these families on a continuum from those who cope well to those who cope poorly.

They profiled the HIV-infected families as "minority families who live in poverty, are often headed by a single woman, have limited resources, continual crises, chronic illness, and few opportunities for social or economic advancement" (p.78). Pediatric HIV families who were able to cope effectively shared certain strengths, such as: (a) having intact support systems (family, friends, church); (b) being able to grieve (for themselves or other infected family members); (c) demonstrating attachment to the HIV-infected child; and (d) being able to meet the day-to-day needs of living (working, providing food and shelter).

They also identified characteristics of families that did not cope well which hindered their ability to manage the disease. These families shared characteristics of: (a) reliance on denial as a coping mechanism that prevented proper disease management and resolution of grief; (b) accumulation of multiple major life crises (i.e. violence, job loss, other family illness); (c) lack of support systems; (d) illness of the biological mother; (e) problem relations with extended family; and (f) construction of artificial barriers to care (i.e. family finds objection to *all* options and attempts at problem-solving).

Reidy, Taggart, and Asselin (1991) interviewed natural caregivers of children with HIV/AIDS to describe perceptions of their psychosocial needs. Natural caregiver was defined as any person, whether biological or other adult in a non-professional relationship, who cared for or participated in the care of the child on a regular basis at home.

Thirty caregivers from 21 Haitian and French-Canadian families participated in this study. All children had been vertically infected and ranged in age from one month to two years. Single mothers headed 50% of the families, most of whom reported being abandoned by partners within 18 months of the AIDS diagnosis in the family.

An open-ended questionnaire was developed and used. Major categories were constructed from classifying concepts from the pediatric AIDS literature according to the five fundamental needs identified by Henderson (cited in Reidy et al.): *the need to maintain physical integrity; to learn; to act according to a set of beliefs and values; to communicate;* and *to feel worthwhile and useful*.

Under Henderson's major category, the need *to maintain physical integrity*, respondents believed the needs to understand HIV transmission, to prevent transmission to others, or to protect the HIV child from opportunistic illnesses were equally important.

However, the natural caregivers felt that their need to know how to protect their child from opportunistic illnesses had been the least satisfied by health care professionals.

In their category of the need *to learn*, it was important for caregivers to obtain honest answers, be informed of the clinical aspects of AIDS, have written information, know how to cope with stress, learn professionals' roles at the hospital, know available support groups, and be included in decisions about which professionals would be informed of the HIV status. Having honest answers and AIDS information were more important than knowing how to cope with the stress associated with the illness. They felt health care professionals satisfied their need for honest answers and for clinical information and had done a good job of informing the natural caregiver about their respective roles.

The category, the need *to act according to a set of beliefs and values*, reflected their need to be respected by hospital personnel for doing what they believed to be *right* was the most important need and the need most satisfied by health care professionals. Interestingly, discussion of death was the least important need of the caregiver and the least well satisfied.

In their need *to communicate*, both formal and informal networks were considered. For the formal network of resource persons, the natural caregivers perceived being kept up-to-date on the child's condition and being able to discuss feelings/reactions were the most important in addition to being the best satisfied. None of the natural caregivers belonged to a parental support group and did not see that as important. In their informal social network, they needed to count on those closest to them, followed by their religious group.

In their last category, the need *to feel worthwhile and useful*, caregivers indicated that support by hospital personnel and availability of childcare services as being the most important needs and best satisfied.

In addition, the natural caregivers identified 24 different needs that could be categorized in three groups: (1) needs for formal support, (2) needs of an emotional nature; and (3) needs of an instrumental or functional nature. For formal support, the needs for continuity of care with caregivers; to develop a relationship with professionals following the family; to see the same person; and to obtain professional assistance in dealing with feelings and fears were identified.

Needs of an emotional nature included the need for help to react appropriately to the child's behaviors related to hospitalization and to be supported and guided in their explanations to the child. Mothers who were sick needed to know who would care for the child after the mother's death, while HIV-positive fathers, whose partners had died, needed a partner to share their lives and regain an active sex life. Instrumental needs of the natural caregivers included the need for household task assistance (especially HIV-positive mothers); transportation to the hospital; help to write letters and pay bills; and financial assistance.

The significance of the study findings is that the natural caregivers, many of whom are also infected, were affected cognitively, socially, and financially. They focused on their most immediate needs: to know transmission and prevention of HIV; to have current, honest information on child's medical status; to be able to count on family; to be emotionally supported in the caregiving efforts; to have continuity of care; and to have financial and physical assistance with home care. Although generalizability of the findings is limited to the sample studied, nearly half the sample were HIV-positive mothers.

Clemo (1992) explored the impact of stigma on infants and children with HIV infection. She specifically investigated whether existing biases and prejudicial fears towards HIV-positive adults affected the political responses to infants and children with HIV/AIDS. She cited current public assistance programs aimed at alleviating or preventing suffering of children as evidence of the government's historical attitude of protectiveness toward children. Clemo proposed that HIV-positive infants and children, infected through not fault of their own, would also warrant protection through government support. The survey of lobbyists was conducted to determine whether HIV adult-based prejudicial attitudes influenced pediatric AIDS legislative issues.

Clemo acknowledged the ideal subject population to be Congressional representatives, but limitations of logistics and concerns over honest responses (likely related to re-election issues) precluded their inclusion. Consequently, lobbyists were approached due to their association with federal decision makers and their freedom from the constraints of media and re-election issues. Two-thirds of the lobbyists described their organization as “promoting interests beneficial to society” (p. 313) with membership between 15,000-20,000; over 90% as having good to strong fiscal standing and moderate to very strong membership participation; with all using a *friendly or informative* approach for persuasion.

The lobbyists reported their effectiveness in influencing HIV/AIDS policies at three percent, but at 71% for efforts in other children's issues. Ninety percent rated policymakers as not having been expedient in formulating or adopting HIV/AIDS policies compared to other policies concerning children.

Sixty-eight percent attributed the government's lack of efficiency in addressing AIDS issues to the policymakers' moral code that ultimately affects their legislative actions. Clemo suggests that the survey indicated stigmatization of the pediatric population due to their association with high-risk populations, quoting national lobbyists that: “politicians view AIDS as a predominately minority, low-income, drug abusers' disease, no matter who the victims are” and AIDS programs for infants and children are a “no win investment” (p.314).

Sherwen, Boland, and Gilchrist (1993) targeted the female caretakers of HIV-positive children. The preliminary data is a component of a larger study comparing psychological family structure variables in three family units: biological, extended, and foster families of children with three chronic illnesses: vertically-transmitted HIV infection (VTHIV), cancer, and sickle cell disease (Table 2). In the three-way comparative study, Sherwen et al. attempted to identify differences in the female caretakers' perceptions of: (a) the child's vulnerability, (b) stressful life events, (c) family adaptation and cohesion, and (d) family coping strategies.

The study (N = 56) investigated biological mothers (n = 21), female extended family caretakers (n = 26), and female foster caretakers (n = 9). Selection was limited to the primary female caretaker of children in the CDC (1987) categories of P1 (infected and asymptomatic) or P2 (infected and symptomatic) who were six years and under. All children were in the chronic phase of HIV infection and managed as outpatients.

Table 2

Three-Way Study Design of Major Study (Sherwen, et al., 1993)

Family Illness	Biological	Extended	Foster
Families/Children with HIV[a]	Group 1	Group 2	Group 3
Families/Children with Cancer	Group 4	Group 5	Group 6
Families/Children with Sickle Cell Disease	Group 7	Group 8	Group 9

[a] = indicates group being described and compared in preliminary findings of Sherwen et al.

Data was collected from primary caretakers during a routine pediatric clinic visit. Instrumentation included: 1) FILE - Family Inventory of Life Events and Changes: perception of stressful life events during last 12 months; 2) FACES III - Family Adaptability and Cohesion Evaluation Scales III: adaptation and cohesion; 3) F-COPES - Family Crisis-Oriented Personal Evaluation Scales: coping strategies; and 4) FCVS - Family Child Vulnerability Scale: perception of child's health related vulnerability. Although the published report does not provide reliability and validity data, all instruments are frequently used in family-related research and demonstrated adequate reliability and validity (Grotevant & Carlson, 1989).

Ninety percent of the sample were African Americans; the remainder identified as Hispanic or White. Caretaker ages ranged from 19 to 64 years of age. Most women reported receiving public assistance and caring for more than one child (infected and uninfected) at home. Between family types, there were no demographic differences in gender of child, employment status of primary caregivers (generally unemployed), or years of education. Differences between family types were noted in child's age (oldest in extended families; youngest in biological families); in symptoms (foster families report more children with at least one related symptom); in age at diagnosis (children in extended families diagnosed at much older age); and in infected adults in the home (biological family with one or two; extended families with one; foster families with none).

Analyses of the findings did not reveal statistically significant differences between family types although examination of individual items suggested overall patterns. For example, extended families may be more compromised and reported greater number of life changes (FILE) and self-perceived being the least adaptive and cohesive (FACES III) of the three groups. All family groups shared similarities in the number of coping strategies used; however, individual item examination indicated that extended families use different strategies than foster families.

The groups also shared similar perceptions of their child's vulnerability, generally denying worrying that the child would die. Biological mothers perceived their child's energy level to be comparable to other children of the same age while the other caretaker groups did not agree to the same extent. The meaning of these findings are unclear and the researchers acknowledge that influences of the caretaker's denial of illness, cultural or socioeconomic status, and value systems are unknown and require further exploration.

While the data analysis did not distinguish differentiating characteristics, the baseline data did suggest that each type of family caretaker faces diverse issues and problems. They also demonstrate strengths. The inconclusive findings suggest that, to fully capture these mothers' caretaking experience, future research may need to include a qualitative component that would allow mothers to tell their own stories.

Melvin and Sherr (1993) presented three case studies from their sample of 31 families (18 with infected children) to examine the psychosocial needs of children with HIV/AIDS. The sample included 14 mothers and 8 fathers who were HIV-positive. The children were part of a longitudinal psychological study based at a London Hospital. Three cases were selected that describe some of the psychosocial challenges facing the family. In each of the cases presented, both mother and child were infected. The researchers reviewed both the child's and mother's needs for each case.

The researchers presented these case studies as preliminary data. Their descriptions highlight critical parenting, separation, dependence, and emotional issues that are likely to face pediatric HIV/AIDS families with multiple infection. Families may have unsupportive home situations, either immediate or extended, or both. Mothers may experience health problems that affect parenting abilities. These health problems are complicated by secondary stresses such as separation, hospitalizations, and fear of the future. The extent to which these factors impact utilization or compliance with health care for the mother or child was not clearly defined.

In 1994, Black, Nair, and Harrington conducted a longitudinal investigation comparing the parenting and early childhood development of the children of two groups of HIV-positive and HIV-negative mothers. One group received a home intervention while a control group did not. The study presented within group (HIV-negative vs. HIV-positive) and between groups (intervention vs control) comparisons. Maternal group demographics did not differ significantly with both groups comprised primarily of single, African American, low income, inner-city, multiparous, drug users who had not completed high school. Although six children were HIV-positive, none were symptomatic during the study period.

Each family was followed by a primary health care provider and social worker with evaluation visits at 3 months (parental stress), 6 months (developmental assessment), 9 months (mother-child interaction), 12 and 18 months (developmental assessments), and 30 months (home visit). Standardized measures used were: Child Abuse Potential Inventory (child abuse potential); Family Support Scales (family support); Family Adaptability and Cohesion Evaluation Scale III (family functioning); Parenting Stress Index (parenting stress); Bayley Scales of Infant Development (developmental status); videotaped observations of mother and child using modified Parent Child Early Relational Assessment (parent-child interaction); and HOME Scales (child-centered quality of the home). Data analysis included examining (1) differences in parent variables and developmental scores; (2) change over time for maternal attitudes and children's developmental status through repeated measures multivariate analyses of covariance; and (3) differences in variables as by HIV status and intervention.

Findings for the groups revealed no main effects related to HIV status or intervention for baseline measures of child abuse potential, family support, family functioning, parent stress, or child stress. At six months, children of HIV-positive mothers had marginally higher scores in mental development than children of HIV-negative mothers, but had significant differences in motor development. There were no significant difference in parent-infant interaction at 9 months, either by HIV status or intervention. At 18 months, HIV-positive mothers receiving the home intervention had more normative scores for child abuse potential than did the control group HIV-positive mothers. Overall, HIV-negative women reported more increases in child-related stress than did HIV-positive mothers at the 18 month period. At 30 months, observations of parenting behaviors revealed that mothers who received the intervention, irrespective of their HIV status, were marginally more likely to have a child-centered home and score higher for maternal emotional and verbal responsiveness.

This study contributes several important findings to the understanding of the relationship between HIV disease as a maternal chronic illness, parenting, and early childhood development. First, there were few differences in parenting attitudes, behaviors, or child development related to maternal HIV status. Second, intervention and maternal support were associated with more optimal parenting attitudes and behaviors. Third, the intervention positively affected changes in attitudes of HIV-positive mothers, but not HIV-negative mothers, regarding parenting and behaviors.

The researchers proposed several aspects of the HIV-positive mother's experience that bear further investigation. First, because the mothers were asymptomatic, it may be possible that their HIV infection may have been too distal to negatively affect parenting. Alternatively, given their existing multiple stressors, HIV-positive mothers may have reached their threshold of stressors whereby their level of parental functioning could not be further undermined. Second, they suggest the possibility that the disease had a positive impact on the mother's lives, particularly their caregiving role. Perhaps in recognizing their own mortality, they were more receptive to the intervention in order to maximize their limited opportunity to parent. One respondent emphasized the importance of her role as mother: " 'When I'm gone, and he's grown, I want him to remember his mother with pride. I know I can't always be there for him, but I'm here now and I'm taking good care of him' " (p.609).

Mellins and Ehrhardt (1994) explored stress and coping among families with HIV-positive children. The exploratory, descriptive study investigated three issues: (1) stressful experiences identified by caregivers, HIV-positive children, and uninfected siblings; (2) family coping with HIV-related stress; and (3) psychosocial needs reported by families.

Fifty-two participants from 25 volunteer families were interviewed. Thirteen families were African-American; seven Hispanic (Dominican and Puerto Rican); and five of mixed ethnicity. Approximately one-third of the families were HIV-positive single parents, another third were extended families, and the last third were adoptive or foster care families. One-third of all families had experienced the death of a parent during the time the child resided with him or her.

Thirty-one caregivers, fourteen HIV-positive children (ages 4 to 14 years), and six siblings (ages 11 to 16 years) were interviewed. Four families had two infected children and one family had three. Children who were too ill or who did not know their diagnosis were not approached.

The investigators conducted open-ended semi-structured interviews. Content analysis was performed to identify major themes. Stressful experiences and coping strategies of the HIV-positive parents, HIV-positive children, and non-positive siblings are reported in Table 3. Only those items identified by more than 50% of parents, children, and siblings are included.

The primary psychosocial needs identified by caregivers (primarily the birth parents) indicated families need professional support, family support, and respite care. Professional support was needed in communicating with physicians and social service agencies. This included access to support groups and family therapy to address issues of child behavior problems and disclosure for both the infected child and uninfected siblings. Caregivers also wanted more emotional and physical support from family members to help in coping with stress and in providing child care. Finally, respite care was the most frequently reported need. The caregivers reported having little time for social activities or their own health care needs. Dangerous neighborhoods prevented children from playing outside without supervision, so both parents and children reported " 'feeling closed in with no place to go' " (p. S58).

Table 3

Stressful Experiences and Coping Strategies Reported by HIV-positive Parents, HIV-positive and Non-positive Children, and Siblings (Mellins & Ehrhardt, 1994)

Stressful Experiences
HIV-positive Parents
Illness management of concurrent illness of parent and child
Stigma associated with HIV/AIDS and risk behaviors; secrecy due to fear of ostracism; disclosure of either child's or parent's HIV status to children
Communication with health care providers; knowledge as parents disregarded
Multiple family infections and deaths from AIDS
HIV-positive children
Siblings & parents death from AIDS; separation due to parent drug use or hospitalizations
Family relationships and conflicts
School problems
Siblings
Same as HIV-positive children; non-positive adolescents include secrecy and anger over the burden of caring for both sick siblings and parents

Coping Strategies
HIV-positive Parents and Family Caregivers
Emotion-focused: use of religion (most important and most helpful strategy); acceptance, distraction, self-reliance
HIV-positive Children
Turning to family, friends, and professionals for support
Fantasy and wishful thinking of desire to be like other children
Non-positive Siblings
Primarily relied on self; reported fewer resources for social support

The researchers acknowledge the limitations of the small sample size and the lack of a comparison group in attributing their results exclusively to the impact of pediatric HIV infection. However, this study identifies some aspects that make pediatric HIV infection unique from other life-threatening illnesses, that is: caregivers are likely to be ill, lack physical/emotional support, or experience compounding stressors of poverty; the infected child may experience multiple deaths (parents or siblings); and sibling(s) may be burdened by caring for ill parents and an infected sibling.

Coping by HIV-positive children was also investigated by Hardy, Armstrong, Routh, Albrecht, and Davis (1994). The researchers compared coping patterns among three groups of 20 preschool children and their parents: those with symptomatic infection; those with a cancer with a mortality rate of less than 40%; and those who were relatively healthy (recruited from a well-child clinic). The study also described patterns of communication between parents and their ill children.

The HIV-positive children were predominantly African Americans in single parent families. Ten were in foster care; seven of those had mothers who died from AIDS. Parents reported five children as being aware of their HIV diagnosis. The children with cancer were mostly Caucasian with married parents; none were in foster care. Fifteen were aware of their diagnosis. The control group consisted of primarily Hispanic children; approximately 50% with married parents. The number of control children in foster care is not known. In recognition of the potential impact of demographic variables on coping, socioeconomic status, ethnicity, and marital status were included as covariates in the analyses across all groups. In their between group and within group analyses, foster care was also included as a covariate.

The researchers adapted the Coping Strategies Inventory (CSI) to measure parent and child coping. The CSI presents potentially stress-producing situations and asks respondents to indicate use of a specific strategy via a five-point Likert scale (1= not at all; 5 = very much). To address the reported difficulty in completion of the CSI by participants with limited education, the researchers decreased the number of items from the original 72 to 32. Reliability and validity for the original CSI was reported, but indicate that psychometric properties for the shortened version continue to be investigated. Parents were asked to fill out both the parent and child versions of the adapted CSI. Results of the child version must be interpreted as the parent's perception of how the child was coping rather than reflecting the child's perception. Consequently, results of the adapted CSI must be interpreted and applied with caution.

The researchers reported the use of two primary coping strategies that reflect disengagement strategies: wishful thinking and self-criticism. Findings indicated greater use of wishful thinking by mothers of both chronic illness groups than those with healthy children. Mothers with HIV children reported more wishful thinking than those with children with cancer.

Self-criticism was the other finding that reached significance. The primary factors related to self-criticism were socioeconomic status (SES) and child's age. Parents of healthy children reported more self-criticism than parents of the other two groups; natural mothers expressed more self-criticism than foster mothers; mothers of HIV children reported more self-criticism than mothers with cancer children. The researchers suggest that parents of lower SES may be critical of their inability to afford preventive care; that parents may be more self-critical when their children are younger; and biologic mothers may be more self-critical since they were the mode of transmission. However, once the demographic variables of SES status and child's age were factored out, these findings only approached significance.

Communication patterns of parents and their ill children focused on the disclosure of illness to the child. Across the disease groups, more children with cancer than children with HIV had been told of their diagnosis. In addition, there was a significant correlation between foster status and mother's disclosure; that is, natural mothers were more likely to discuss the illness with their children than were foster mothers.

There are several limitations of the published report that affect the reader's ability to interpret findings. First, no reliability and validity is provided to support their major adaptation of the original CSI although it was the primary measurement instrument for coping. Second, the findings refer to secondary and tertiary levels of coping factors which are reported as not having significant differences, but are not defined. Consequently, it is difficult to ascertain the significance of that finding. Third, there is no discussion or definition of the major concepts of wishful thinking and self-criticism which they present as major findings of the CSI.

An important issue raised by this study is the disclosure of the diagnosis to the infected child. While oncology physicians made significant efforts to explain the children's diagnoses to them, the immunology (HIV) physicians reported that most of their discussions occurred without the children. The physicians reasoned that children were " 'not to be trusted with a secret that could result in ostracism from the family and/or community' " (p.S52). Previous studies indicate that children are aware of their illness and dying, despite parental efforts to keep the information from them (Bluebond-Langer, 1978; Waechter, 1971). This raises the question of what these infected children actually know about their illness.

Barrett and Victor (1994) published preliminary findings from their study of VTHIV families who discussed their experience with health care services and their feelings about HIV. The sample consisted of ten parents of VTHIV children from the hospital's total pediatric HIV caseload of 97. The children ranged from 5 months to 11 years of age; six were identified as from Sub-Saharan Africa. Of the ten, six lived with both parents and three had both parents with HIV.

For seven children, entry into the HIV pediatric unit followed the child becoming ill. Parents reported satisfaction with the HIV outpatient clinic care and felt the child was receiving the best care available in the country. However, outside the hospital, parents reported rejection from their own general practitioner (GP) following their diagnosis, but were precluded from registering with a GP sympathetic to the needs of HIV-positive persons because they were outside his practice area.

In seven families, the first indication of HIV infection was the child's illness, although it is not clear if that was also the first indication of parental infection. Parents attributed their satisfaction with the pediatric health care team to their patient and caring attitudes, willingness to address all issues, and level of HIV/AIDS knowledge. Parents experienced stigmatizing attitudes from other hospitals, such as being made to feel uncomfortable or having some staff refuse to provide care.

Parents reported problems in managing multiple appointments at different sites. They felt adult and pediatric clinics should be separate as “the people in the clinic (i.e. gay men, with AIDS, very ill) is frightening” (p.429) to the child. Parent also felt it important for the care to be family centered as the effect on one member ultimately affects them all.

Throughout the course of the interviews, families expressed their feelings about HIV and the effect it has had on their lives. While families were generally positive about their problems, they expressed great anxiety and uncertainty as well. One great source of anxiety was the potential for the concurrent hospitalizations of parent and child. Most families felt the mother becoming ill caused more problems than fathers being ill, especially in families where fathers had little involvement in domestic tasks and childcare. Comments of not having much time; not being accepted; trying to keep charge of their life; wishing to die quickly versus a lingering illness; and contemplating suicide provided insight into the diverse pressures that HIV/AIDS place on families.

HIV-Positive Mothers with HIV-Positive Children

Andrews, Williams, and Neil (1993) published preliminary descriptive data from a larger study of HIV-positive mothers and their children. Preliminary descriptive findings focused on the unique character of the mother-child relationship in the HIV-1 positive family and the impact of the relationship on the mother's reaction to her illness.

The preliminary descriptive analysis included 72 mothers recruited from a pediatric AIDS clinic. The mean age of subjects were 30.3 years. African Americans comprise 56%, Whites 25%, and Hispanics 18% of the sample. Thirty-seven percent were currently using drugs/alcohol, 38% formerly used drugs, 15% never used drugs, and 10% were currently receiving methadone.

Medical records, the Norbeck Social Support Questionnaire, the Addiction Severity Instrument, and an open-ended interview were used in the data collected to describe the experience of the HIV-positive mother. Only the content analysis of the interviews were reported.

Preliminary findings identified two major categories: the *mother/child relationship perceived as supportive* and the *mother/child relationship perceived as burdensome*. In general, the mother/child relationship revealed a strong attachment between mothers and their children whether or not they lived together. More than one-third of mothers listed children under 16 years of age as sources of support and, much like the Melvin and Sherr case study, some were younger than eight years. These mothers also felt bound to their children through the secrecy necessitated by the stigma of HIV/AIDS. Only 33% of children under 16 years old were aware of their mother's positive HIV status.

The *mother/child relationship perceived as supportive* revealed that children provide support for their HIV-positive mother by: (a) decreasing feelings of isolation and providing a reason to remain attached to the world, (b) forcing mothers to remain positive about life, (c) increasing self-esteem by fulfilling the role of motherhood, and (d) providing an impetus for mothers to cease high-risk behaviors.

The *mother/child relationship perceived as burdensome* was based on two related concerns: (a) anxiety due to placement of surviving children and (b) fear for HIV-positive child's disease course, effect of long hospitalizations, and their eventual death. Other mothers, however, characterized the relationship as burdensome due to: (a) having to deal with the eventual placement of surviving children, (b) their fear for the HIV-positive child's health and eventual death, (c) decreased maternal privacy, (d) the lack of childcare, and (e) dealing with children's angry and hostile reactions to the mother's HIV infection. After spending much of their energy protecting children from discrimination or stigmatization, guilt, grief, and exhaustion left them little energy for themselves. Despite the burdensome aspects of this mother-child relationship, the HIV-positive mothers expressed their desire to maintain a relationship with their children.

One study of pediatric HIV/AIDS families with an HIV-positive is currently pending publication. Their discussion is limited to the information provided in the study abstracts. Weiner et al. (cited in Cohen, 1994) investigated 101 parents whose child was an HIV clinical trial participant of the National Cancer Institute. Parents were investigated for anxiety, depression, coping, and anticipatory grief. The sample included biologic and adoptive/foster families, and extended family members. HIV status of biologic parents was not stated.

The study used the Spielberger State Trait Anxiety Inventory to measure parental anxiety. Parents scored high on both state and trait anxiety but when compared to general medical patients, state anxiety was significantly higher for parents of HIV-positive children. The Beck Depression Inventory was used to measure parental depression with nearly 25% indicating moderate to severe depression. Parents of the HIV-positive children reported more depressive symptoms in the clinical range than mothers whose children were treated for cancer. The Parental Coping Scale's negative affect component increased significantly as the child increased in debilitation. The Anticipatory Grief Scale was adapted for this study and indicated a significant increase in anticipatory grief when children were over 11 years of age, but not affected by the degree of the child's debilitation.

The study by Cohen, Nehring, Malm, and Harris (1995) reports the findings of a larger, ongoing study to compare family environment and supports of biologic and foster HIV pediatric families with a control population. The findings report issues experienced by a smaller sample of four biologic and four foster families. Ten parents from eight vertically-transmitted HIV (VTHIV) families were interviewed. Data was collected using semi-structured interviews. Biologic families included two white, one Hispanic, and one biracial; foster families included three white and one African American.

Content analysis revealed major themes for both natural and foster families. In the biologic families, all mothers expressed guilt. Biologic families felt that mother and child had a special relationship and felt that they faced an uncertain future, living from day to day. A major fear was preceding the child in death and, thus being unable to provide comfort to the child as he or she was dying. In the foster families, the natural children felt an initial uneasiness about the HIV-positive foster child, primarily regarding the fear of transmission. Ultimately, however, the natural children accepted the child and became an asset in their care.

This study identified issues common to both types of families with VTHIV children. For example, both feared disclosure of having an HIV-positive child due to potential consequences of isolation, stigma, job loss, friend loss, or even eviction. Families lived for the present while facing an uncertain future.

In their investigation of mothers with HIV/AIDS, Rose and Clark-Alexander (1996) propose to empirically measure their coping behaviors. Fifty-two HIV-positive mothers of which 65 % were African American, 23% white, and 12% Hispanic. The mean time since their diagnosis was 2.3 years. Seventy-five percent were single; mean educational level was almost 11 years. Modes of transmission were primarily heterosexual contact (44%) and injection drug use (33%). Respondents had one to seven children whose HIV status was not specified, but for whom reference was made regarding the "children's HIV-positive status" (p.45).

The Jalowiec Coping Scale was the measure for maternal coping. Correlations between behaviors and coping styles were presented in their findings. Generally, those who engaged in drug and alcohol engaged in more passive coping styles, while those who practiced meditation used more confrontive coping styles. The researchers propose that use of relaxation training as a possible coping method to encourage problem-focused (illness management) coping ability and skills.

Summary

This review emphasizes the paucity of research literature available on pediatric HIV families, especially those with an infected mother. It identifies limitations of current research and emerging areas for future research.

Pediatric HIV/AIDS families, like other families facing life-threatening chronic illnesses, find themselves challenged by the stresses related to the diagnosis, isolation, treatments, clinical spectrum, and fatal outcome of the disease. However, when the illness is HIV infection, some themes may share common aspects but the impact of HIV is not known and so requires further exploration. For example, both chronically ill and HIV pediatric families reported increased isolation. For the parents of children dying of cancer, isolation was related to having less time due to caregiving responsibilities and spending more time with the family; possibly even due to unresolved anticipatory grief leaving the parent with less energy for friendships and social activities (Koocher & O'Malley, 1981). Families of HIV-positive children also report experiences of isolation. While their experiences may be attributed to their burden of caregiving, recurrent reports of rejection by family and friends due to the stigmatization of the disease add a new dimension to the experience of isolation (Andrews, Williams, & Neil, 1993; Brown & Powell-Cope, 1991). Such stigmatization results in secrecy that not only prevents disclosure of diagnosis to families and friends, but to the child as well.

Pediatric AIDS families are often comprised of the mother-child dyad, but may include foster parents or extended family members. As caregivers, the pediatric HIV family groups reported issues similar to other caregivers of children with chronic, life-threatening illness such as (a) experiencing their time orientation in the present and (b) managing caregiving with limited emotional and physical resources. Dimensions of the caregiving experience unique to the HIV pediatric family is the secrecy surrounding this illness. For the HIV-positive mother, the feelings of sorrow and loss are compounded by secrecy, forcing her (or other primary caregivers) to suffer feelings of guilt, blame, and grief alone. In addition, VTHIV families are more likely to experience the death of several family members.

Further, while the family's socioeconomic status and social support resources affect any family's ability to manage illness, the literature indicates that pediatric AIDS families are likely to be headed by single, poor women of color. Strained financial resources are reported by both chronic illness and HIV pediatric families as they experience job loss or unemployment that impact the financial stability of the family. HIV pediatric families reported reliance on government assistance programs for almost all aspects of their lives: food, shelter, and medical care. Although race and ethnicity are not risk factors for HIV transmission, African Americans and Hispanics comprised 80.3% of pediatric AIDS cases (CDC, 1996) and comprised 62% of those living below the poverty level in 1992 (CDC, 1994). For them, financial hardship may not be a result of their illness, but rather reflect their economic reality of continuing poverty that is compounded further by illness.

CHAPTER THREE

METHODOLOGY

This chapter presents the qualitative research methodology used to explore and describe the experience of the HIV-infected mother whose child is also infected. The methodology will be discussed in the following major sections: (a) the research design, (b) description of setting, (c) sample, (d) data collection, (e) procedure, and (f) data analysis.

Research Design

The research design was a cross-sectional study of HIV-infected mothers with infected children purposively and conveniently sampled from the five counties of the San Francisco Bay Area and Sacramento County. Data collection consisted of semi-structured interviewing at a mutually agreed upon meeting place. The qualitative analytic technique for the data analysis was content analysis.

Description of Setting

The target areas were the San Francisco Bay Area counties (Alameda, San Mateo, Contra Costa, Santa Clara, and San Francisco) and Sacramento County. These counties comprised a wide range of ethnic groups and socioeconomic levels. Each has several major HIV/AIDS resource centers through which subjects were recruited.

Sample

The target sample was the HIV-infected mother who had an HIV-infected child less than 13 years of age at the time of the interview. The sampling aim was to select an approach which would garner subjects who can provide accounts of their world true to the phenomena under study (Hammersley & Atkinson, 1983). Random sampling within this population would have been impeded by the limited number available and the inability to readily identify subjects due to issues of confidentiality (by agencies) and fear of disclosure (by clients). Therefore, the research effort relied on purposive, convenience sampling. It was anticipated that snowball sampling, where an initial contact becomes a base for recruiting additional subjects, would provide additional respondents.

Human Subjects Assurance

Permission to conduct the research was obtained from the Committee on Human Research (CHR) at the University of California, San Francisco. After obtaining permission, subjects were recruited from various AIDS support agencies throughout the six counties by posting flyers at each site. An advertisement was placed in a widely circulated newsletter targeting women with life-threatening illness, primarily AIDS. Recruitment from both sources provided within-sample diversity, either by ethnicity, socioeconomic status, education, or family structure.

Mothers were given $25.00 per hour for each interview to be paid *before* the interview began; a minimum of two hours was advanced. She was informed that she did not have to answer any questions she did not wish to and could discontinue the interview at any point.

Informed consent was obtained from all participants and filed separately from the data. Each woman received her own copy of the consent form as well as a written explanation of the study.

Potential discomforts and risks to subjects. There was some discomfort to the mother as she was asked to think about their current life difficulties and challenges, the impact of their HIV diagnosis, her child's current and future life, and her strategies to manage them. Some of the questions made her uncomfortable or upset, but she was free to decline to answer any questions. None of the mothers declined to answer any questions nor prematurely terminated the interview.

Risks in participating in this study were the potential loss of privacy or confidentiality. Data was kept confidential as much possible. No individual identities were used in any reports or publications resulting from this study. Field notes and transcriptions from the audiotapes were coded with numbers and no names appeared in them. Coded names of informants were available to the researcher only. After completion of the study, tapes will be destroyed. Data will be kept at all times in a locked and confidential file accessible only to the researcher.

Sample Strategy and Size

The initial aim of sampling was to obtain a convenience sample of mothers, likely relying on a snowball or chain sampling technique, seeking to identify *typical cases* at first. At the point key concepts, behaviors, or patterns emerged, the sampling became theoretically driven (Strauss & Corbin, 1990). Per theoretical sampling, choices for sampling were driven by the emergent data and not by a quest for representativeness. One type, ***maximum variation sampling***, was a deliberate search for variations in the emergent data or to see whether important patterns and behaviors hold by deliberately seeking a heterogeneous sample (Morse, 1994). It included searching for confirming and disconfirming cases and extreme or deviant cases to elaborate the initial analysis, looking for confirmation or exceptions and variations.

How many cases, then, would be enough to give confidence in the analytic findings? There was no set criteria. Data was generated until the researcher experienced repetition in the ongoing analysis (saturation) which did not appreciably add to the findings. That was the point at which the sample size was considered the most efficient (Strauss & Corbin, 1990). For this study, the sample size was twenty respondents.

Credibility of informants. In using paid informants, the issue of their credibility arises. No medical records were reviewed in this study, consequently mothers were self-identified. The primary issue was whether the women were mothers of HIV-infected children. Initial phone screening emphasized that physical as well as psychosocial aspects of their child's illness would be a major focus of the interview. Because the pediatric and adult disease differ by course of illness and treatment, questions related to all aspects of pediatric HIV infection were casually included throughout the interview. The interviewer sought consistent and knowledgeable responses.

Criteria for Sample

HIV-infected, caregiving mothers with infected children were targeted for inclusion in this study. Age was not an exclusion factor for mothers; however, consistent with the 1994 CDC definition of pediatric, the child must have been less than 13 years old at the time of their interview with the researcher. Subjects were limited to those who were English speaking.

Data Collection

It was from the respondents' world of meanings, actions, and interpretations that key concepts were derived. Obtaining such data relied on the naturalistic inquiry process in which there was no manipulation on the part of the investigator, as well as no imposition of a priori notions on the outcome (Denzin, 1989). Data collection method was the semi-structured interview. Denzin and Lincoln (1994) summarize it best:

> The interview is a conversation, the art of asking questions and listening. It is not a neutral tool, for the interviewer creates the reality of the interview situation...the interview produces situated understandings grounded in specific interactional episodes. This method is influenced by the personal characteristics of the interviewer, including race, class, ethnicity, and gender. (p.353)

Technique

Data related to age, gender income, ethnicity, and other demographic variables to describe the study sample followed a structured format during the initial part of the interview. Data collection related to the study purpose relied on in-depth interviewing following a semi-structured interview format with open-ended questions. The interview followed a list of guide questions that outlined topics and issues so that data collection was systematized to the extent that the same topics were covered with each respondent. While all were asked the same questions, the phrasing and ordering of those questions was adapted to each interviewee.

Interview: Open-ended, Semistructured

The interview format was adapted from a pilot study of HIV-infected mothers and children (Armstrong, 1994). To address content validity of the interview tool, two nursing research experts in childhood cancer and two HIV/AIDS women's clinical nurse specialists or practitioners were given the format for review and comments. Two HIV-infected mothers were selected to complete the interviews as well as suggest additional dimensions/perspectives of the disease not addressed in the interviews.

The Qualitative Analytical Technique: Content Analysis

Qualitative data analysis is the process of bringing order, structure, and meaning to the data collected. Qualitative data analysis categorizes data, searches for relationships, and/or builds theory. The data collection and analysis are a simultaneous, non-linear process (Marshall & Rossman, 1994). As data collection and analysis continues, categories or concepts may be altered, discarded, or reconstructed (Strauss & Corbin, 1990). The plan for analysis is derived from the research purpose, design, method of data collection, and the level of measurement used.

Qualitative analysis plans are distinguished as *descriptive* or *inferential*. *Descriptive analysis* produces description of the prescribed sample. *Inferential analysis* produces statistical data from the prescribed sample to support inferences about the total population (Brink & Wood, 1988). Consistent with this study's research design, a descriptive analytical method was used, specifically *content analysis*. Its method and operations (data reduction, data display, and formation of conclusions) are discussed in the following sections.

Definition

Recorded words and sentences provide rich and holistic data about humans and the social and cultural contexts in which they exist. The words and sentences that result from the open-ended questions are unstructured, textual data. The process of structuring this unstructured data allows the researcher to identify, measure, and describe characteristics reflected in the written texts. This process is called *content analysis* (Catanzaro, 1988). It may be used both inductively (theory-building form categories evolved from the data) or deductively (theory-testing from categories established before data analysis).

There are two types of content analyses: manifest and latent. In *manifest content analysis*, the researcher applies statistical methods to textual material to make inferences. Analysis is done at an obvious level, such as coding and counting specific units (words, themes, time/space measures) in an interview or other text. It has numerical objectivity, but does not consider the context in which the unit of analysis occurs (Waltz, Strickland, & Lenz, 1991).

In *latent content analysis*, the researcher views the textual material within the context of the entire text (Woods & Catanzaro, 1988). Analysis involves making inferences about what was actually stated. The researcher makes no attempt to quantify the number of times the data supports a particular code or category. Because it will be necessary to infer meaning from the words the mothers use to tell their stories, this study applied latent content analysis.

The substantive area of this research was the experience of being an HIV-infected mother with an infected child. The study focus was to provide a description from recorded interviews that have been transcribed into text. Operations for all content analyses occurred in three phases: data reduction, data display, and conclusion formation and verification.

Procedure

Data reduction. Data reduction refers to the process of selecting (defining the content to be examined), focusing (specifying the characteristics or concepts to be measured) and transforming of data (coding or categorizing textual data) that appear in field notes or interview transcriptions (Miles & Huberman, 1994).

Selecting and focusing. The study purpose was to describe the experience of the HIV-infected mother who also has an infected child. Her story, told in her own words, contained the content to be examined. All of the transcribed interviews were analyzed. Concepts and characteristics described included, but were not limited to, the chronic illness concepts previously discussed. Other characteristics unknown at the outset, but discovered during the ongoing analysis, were included as they were revealed.

Transforming data. The process for transforming data was coding. This process followed the technique of *open coding* as operationalized by Strauss and Corbin (1990). They provided the following principal definitions. *Concepts:* conceptual labels placed on discrete happenings, events, and other instances of phenomena. *Category:* classification of concepts (concepts that pertain to a similar phenomena), these concepts are then grouped together under a higher abstract concept called a category. *Coding:* process of data analysis. *Open coding:* process of breaking down, examining, comparing, conceptualizing, and categorizing data. *Properties:* attributes or characteristics of a category. *Dimensionalizing:* process of breaking property down into its dimensions.

The process of coding included naming, labeling, and categorizing data. During the data analysis, the data was categorically organized, repeatedly reviewed, and continually coded. Initially, the written text was searched for leads, ideas, and issues, primarily through line-by-line, sentence or paragraph, or entire document analysis. Key words, actions, phrases, ideas, or events were labeled as concepts and noted on the document.

These notes were taken from the document and became *code notes*, a type of written record called *memos*.

Categories were developed from the labeled concepts. The name assigned to the category was more abstract than the concepts it covered. The name reflected the data it represented and some were borrowed from the literature. However, some were phrases used by the respondents themselves, also referred to as "in vivo" codes (Strauss & Corbin, 1990). Categories were then broken up and refined into subcategories. The subcategories were then expanded in terms of their properties and dimensions.

Reliability and Validity Issues

Reliability of the category coding system was determined by its unitizing reliability (consistency in what is to be coded) and its interpretive reliability (consistency in assignment to categories) (Garvin, Kennedy, & Cissna, 1988). Unitizing reliability addressed two factors: the degree of researcher inference required to identify what is to be coded and the type or form of the data. In order to decrease the amount of researcher inference required (and thereby increase unitizing reliability), the rater was instructed to use line-by line analysis to identify the units (words, phrases, behaviors) related to the question asked. Not every behavior required coding, but rater inference was required. The form of data that could be reviewed repeatedly increased the unitizing reliability. In this study, audiotapes and transcribed interviews were available for repeated examination during coding.

Interpretive reliability assured that the codes were being consistently applied to the units. Interpretive reliability occurred on two levels: global and category-by-category. The measure of global reliability is the degree to which coders consistently code categories. Category-by-category reliability refers to the coders' ability to consistently use categories. To obtain intercoder reliability, one expert nurse researcher and one HIV nurse practitioner or clinical nurse specialist for women read the study findings. They then read a respondent's transcript to determine whether they agreed with the category codes.

Conclusion Formation and Verification

The third phase of analytic activity was conclusion formation and verification (Miles & Huberman, 1994). Its purpose was to draw conclusions or inferences about the meaning of the data. Techniques for drawing conclusions from qualitative data are designed to conceptualize categories from the informant's words. For this study, as conceptual codes and categories were developed, the researcher attempted to establish patterns or themes. The tactics for generating meaning included counting, noting patterns and themes, seeing plausibility, clustering, making metaphors, splitting variables, searching for social processes, factoring, noting relationships between variables, finding intervening variables, building a logical chain of evidence, and making conceptual or theoretical coherence.

Conclusions were also verified as the analysis proceeded. The process of verification are significant issues for any study, quantitative or qualitative. While some researchers have applied quantitative standards of reliability and validity to qualitative efforts (Denzin, 1978; Duffy, 1985), others propose that determination of credibility and evidence is a more appropriate fit to qualitative efforts (Chenitz & Swanson, 1986; Sandelowski, 1986). The following section will discuss the principles of reliability and validity in research as it applies to qualitative research in general and how it was applied to this study specifically.

Trustworthiness

Substantive differences in the purposes of quantitative and qualitative research have been addressed in the literature (Leininger, 1985, 1992; Patton, 1980; Sandelowski, 1986). Because of the differences, tests of methodological rigor applied to quantitative research are inappropriate when applied to qualitative studies.

The criterion of reliability in quantitative research is determined by the ability to consistently and accurately measure and attribute (Polit & Hungler, 1987). However, qualitative research emphasizes the identification of the uniqueness of human experiences and their documentation. Lincoln and Guba (1985) propose the basic issue facing the qualitative researcher as one of trustworthiness: How can the researcher demonstrate that the findings are to be trusted, that they are worth taking into account? They further propose that trustworthiness is established by using techniques that provide (a) truth value through credibility, (b) applicability through transferability, (c) consistency through dependability, and (d) neutrality through confirmability.

Reflexive journal. Maintaining maximum control over research experiences requires an efficient system to record them. Therefore, this researcher maintained a reflexive journal, or diary, of schedules (dates, names, places) and analytic memos (field experiences, insights, and reasoning related to different aspects of the research process). This journal was used to support all aspects of the study's trustworthiness: credibility, transferability, dependability, and confirmability.

Truth Value

The truth value of qualitative research, its credibility, relies on the ability of the researcher to demonstrate that the inquiring was conducted so that the subject was accurately identified and described. Credibility is established when the people having the same experience can recognize it from the findings and when other people recognize the experience after having only read about it (Sandelowski, 1987). The following techniques establish the truth value or credibility of naturalistic inquiry: (a) peer debriefing, (b) referential adequacy, and (c) member checks. Their role in establishing credibility as discussed by Lincoln and Guba (1985) and their general application to the proposed research follows.

Peer debriefing. This technique was useful in establishing credibility by allowing a neutral peer with only a general understanding of the study to ask probing questions, explore emerging concepts or hypotheses, and provide alternative explanations. Both parties maintained written notes (memos) of each session to be used in reflection and as part of the study's *audit trail*, a technique used to determine dependability and confirmability of the study.

Referential adequacy. Referential adequacy refers to contextual materials that the researcher used to support data analysis, interpretations, and audits. Obtrusive measures are videotaping, photographing, or audio taping, specifically done by or for the researcher. Unobtrusive measures include materials produced without reference to the researcher (e.g. written texts, photographs, yearbooks). This study relied on audio taping for referential adequacy for later examination, comparison, or audit.

Member checking. Lincoln & Guba (1985) hold this technique to be the most important in establishing credibility. It is at this step where the original informants determine whether the findings accurately represent the experience. The researcher then weighs the meaningfulness of the member responses to the questions: Does the member audience recognize the phenomena? Does the analysis help the audience explain their own experience? Given the uncertainty of the target population's availability for member checking following the data analysis, the researcher evaluated respondents for potential inclusion, maintaining such information in the journal.

Applicability

The applicability of findings is determined by its ability to be transferred (generalized), to fit into similar contexts. Establishing *transferability* is linked to the condition of representativeness of the data: Are the characteristics of the original sample fully described to permit comparisons with other samples? Threats to the representativeness of the study concern *elite bias* and *holistic fallacy* (Sandelowski, 1986). Individuals who agreed to be subjects may share qualities of being articulate and accessible, and perhaps may even be the higher-status members of their group, causing an *elite bias* of the sample. *Holistic fallacy* is the tendency of the researcher to present the data as being more patterned or congruent than they are, causing the findings to be flawed. For this study, techniques to establish transferability included the use of *thick description* and *purposeful sampling*.

Thick description. This technique required the researcher to move beyond mere fact-recording notes and include contextual, descriptive writing to give the reader a feel for what it is like to be in that context. According to Lincoln and Guba (1985), what constitutes appropriate thick description is not yet resolved. They suggest that thick description should include the widest possible range of information that may be obtained using purposeful sampling.

The threat of *holistic fallacy* (how close interpretation of data comes to capturing the human experience of the HIV-infected mother with an infected child) was addressed by asking two experts to review the results section and one interview transcript. The experts consisted of two HIV/AIDS clinical nurse specialists for women (one available at the target site) and one infected mother who was not a study respondent. Each was asked how close the study came to reflect their experience with HIV-infected mothers and how well the categories came to capturing their experiences.

Purposeful sampling. *Elite bias* was addressed by an ongoing analysis of demographic data (e.g. socioeconomic status, ethnicity, marital/partner status) to increase representation or to acknowledge such bias in the findings. Maximum variation sampling, which provides the means to explore the broadest range of experiences of the respondents, was used throughout the data collection in this study.

Consistency

The issue in determining consistency is whether the process of the study is consistent, that is, stable over time and across researchers. In quantitative research, this is determined by the study's replicability in which "essentially similar inquiry processes under essentially similar conditions yield essentially similar findings" (Lincoln & Guba, 1985, p.299). However, qualitative efforts emphasize the identification of the uniqueness of human experiences and their documentation. Guba and Lincoln (1981) proposed that reliability in qualitative research be measured by its auditability, that is, the ability of subsequent researchers to reconstruct the study's process and logic and thereby arrive at comparable conclusions given the original data, perspective, and situation. The technique used for this study was the inquiry audit.

Inquiry audit. The inquiry audit allows subsequent researchers or an auditor to determine the dependability of the research. It is encumbent on the researcher to provide the auditor with adequate information revealing how and why findings were reached. Consequently, it is important that the original researcher maintain records that provide the auditor with an *audit trail* that allows the auditor to reconstruct the research experience. Lincoln and Guba (1985) propose that the researcher provide such an *audit trail* by maintaining *files that represent the phenomena* and *files that represent the procedures*.

Files that represent the phenomena are: raw data files, data reduction files, and data reconstruction files. *Raw data files* that contained the information from which all study findings were derived, such as interview guides, field notes, memos, and tape recordings or other documentation of interactions were kept. They contained the items and dates that documented the process sequence. Data reduction files contained the materials that were used to manage the large amount of data, such as indexing cards, peer debriefing notes, category development strategies, and visual displays of the data. *Data reconstruction files* were used to track the themes from their emergence from raw data to formation as major themes, such as data analysis sheets, theoretical notes, visual displays of relationships between categories, or preliminary reports of findings.

A separate log was maintained that represented the procedures of the study included: process notes, notes about intentions and motivations, and copies of instruments and resources. *Process notes* were kept about decisions regarding procedures, strategies, or other operational decisions. They included steps that were taken to enhance credibility, dependability, and confirmability. *Files about intentions* and motivations included the original research proposal, personal notes about feelings, biases, thought processes of the researcher and their influence on the study. Finally, a *file of instruments* contained the key questions that guided the inquiry, the preliminary interview guides, and instrumentation used in data collection and analysis.

Neutrality

The concept of neutrality encompasses the *freedom from bias* in the research process and findings. Confirmability is the criterion of neutrality in qualitative research and is established when auditability, truth, value, and applicability are established (Sandelowski, 1986). The issue is whether the study findings are relatively neutral; having reasonable freedom from researcher biases. For this study, the major techniques to establish confirmability were the confirmability audit, triangulation, and the reflexive journal (Lincoln & Guba, 1985).

Each technique has been presented in the previous discussions of truth value, applicability, and consistency. The confirmability audit dovetails with the previous discussion of the audit trail and therefore is not presented independently.

The reflexive journal provided a means of documenting researcher efforts to achieve trustworthiness. No study is value or bias free. The researcher acknowledged the natural subjectivity that existed throughout the study; initially, as empathy for the HIV-infected mother as entry into her world was gained, and, later, as understanding of her experience emerged. What was required of the researcher was to be reflexive in views, thinking, and conduct to continually raise awareness of personal biases.

Summary

This chapter presented the qualitative methodology to explore and describe the experience of the HIV-infected mother whose child is also infected. A discussion of the qualitative and quantitative paradigms included the rationale for selecting a qualitative approach and study design. The research design was presented, including sampling, data collection, and data analysis. Finally, strategies related to establishing the trustworthiness of the study were provided.

CHAPTER FOUR

RESULTS

The purpose of this research study was to describe the experience of the HIV-ositive mother who also has an HIV-positive child. This chapter describes the mothers' elf-reported experiences and perceptions from the time of their HIV diagnoses through heir current experiences caring for their children with HIV infection or AIDS. Their xperiences span the time period from late 1988 through August 1996.

The data will be presented in two major sections: (a) sample description and (b) najor categories. In the first section, the sample description provides the characteristics as vell as contextual information related to the family and health of the HIV-positive mothers vho volunteered to share their experiences. In the second section, major emergent ategories of the mothers' experiences, along with their related concepts, properties, and imensions will be presented.

Sample Characteristics

The women who bravely stepped forward to participate in this study expressed heir desire to help other HIV-positive mothers who also had an HIV-positive child. Mothers hoped that sharing their experiences would increase awareness of the uniqueness of the phenomenon of the mother-child infection; that is, its uniqueness from the experience of being an HIV-positive woman and its uniqueness from the experience of being an HIV-positive mother with HIV-negative children. Ultimately they hoped that telling their stories would result in the development or allocation of resources addressing needs specific to the dual infection of mother and child.

Twenty mothers, each having one HIV-positive child, constituted the sample for this study. All mothers who participated contacted the investigator and self-identified themselves as HIV-positive mothers with an HIV-positive child. Interviews were conducted from October 1995 through December 1996 and took place in the respondent's home or a private conference room at a local hospital facility.

All mothers expressed concerns regarding confidentiality. To assure anonymity, each mother was assigned an identification code which included her age, child's sex and age (years.months). For example, a 42 year old mother whose HIV-positive child was a five month old girl would be identified as 42FO.5. In order to maintain the individuality of the respondent while ensuring confidentiality, this coding sequence was utilized whenever the discussion required reference or attribution to specific respondents.

The women who participated in this study are profiled in the following sections. A contextual description is presented by their composite personal, family, and health profiles. Personal profiles include age, ethnicity, children in home, partner status, income, education, religion, and residence data. Family profiles describe household composition and children in the home. Health profiles include transmission risk factors, timing of diagnosis, general health, and current treatments for both mother and child. Individual personal and health profiles for mother-child dyads are provided in Appendices D and E.

Personal Profiles of the HIV-positive Mothers with an HIV-positive Child

The collective personal profiles of the HIV-positive mother and her HIV-positive child include demographic information such as ethnicity, age, education, partner status, income, religion, and housing (Table 4). Marital or partner status, both at the time of

diagnosis as well as the present, are reported. Individual profiles of mother-child dyads are provided in Appendix D.

Ethnicity. Thirteen of the respondents self-identified as African American, four as Caucasian, and three as Hispanic. Of the three women identified as Hispanic, two self-dentified as Mexican American and one as Honduran. All mothers were fluent in English.

Age. The mothers ranged from 22 to 45 years of age with slightly more than half of the group between 30 and 37 years. The median age was 34.5 years; the mean age was 34.3 years.

Education. Five mothers reported not having completed their high school education while six were high school graduates. In addition to high school, one mother had vocational training (nursing assistant) and one had an associate degree (medical assistant). Six mothers completed from one to three and one-half years of college education. One mother had a Bachelor of Arts degree.

Partner/marital status. At the time of diagnosis, 10 mothers were either married to the father (n = 4) or living with the father (n = 6) of their HIV-positive child. Currently, following the HIV diagnosis, only one remains married and one lives with the same partner. Three others are single with an identified partner.

Income. Of the 20 mothers, 18 reported government assistance as their primary source of income, generally supplemented by other government programs such as Aid to Families with Dependent Children, Supplemental Security Insurance, or Section Eight (housing assistance). One mother, serving a sentence in a California Department of Corrections mother-child detention center, reported no income. One mother had full-time employment and received no supplemental financial assistance. All mothers reported receiving financial assistance from family members at some point since their diagnosis. All mothers also identified participation in research projects and lecture presentations to secondary schools as additional sources of income.

Religion. All mothers but one reported believing in God. Eleven mothers participated in organized religious groups identified as Baptist, Catholic, or non-denominational community groups. Eight did not identify an affiliation with any organized religious group. One mother reported participation in the Jewish religion while growing up although she was no longer associated with any organized group. One mother did not believe in God.

Housing. Twelve mothers maintained their own residence while one mother shared a residence with her mother-in-law. Three mothers resided in drug and alcohol recovery residencies. Three mothers lived in housing provided specifically for people living with AIDS. One mother lived with her child in a California Department of Corrections mother-child detention facility. One mother resided in a drug recovery rehabilitation group residence.

Table 4

Personal Profile

Demographic Description (n = 20)		n	(%)
Ethnicity	African American	13	(65)
	Caucasian	4	(20)
	Hispanic	3	(15)
Age	Range: 22-45		
	Median: 34.5		
	Mean: 34.35		
Number of Years of Education	<12	5	(25)
	12	6	(30)
	12 + Vocational training	1	(5)
	13-15	7	(35)
	College Graduate	1	(5)
Partner Status	Married	1	(5)
	• *before diagnosis*	*4*	*(20)*
	Single, living w/partner	1	(5)
	• *before diagnosis*	*6*	*(30)*
	Single, with partner	3	(15)
	Single, no partner	15	(75)
Source of Income	Government assistance programs	18	(90)
	Full time employment	1	(5)
	No income	1	(5)[2]
Religion	Identified religious organization	7	(35)
	Non-denominational organization	4	(20)
	Belief in God, no group specified	8	(40)
	No belief in God	1	(5)
Housing	Maintain own residence	12	(60)
	Share w/other family	1[1]	(5)
	Drug/Alcohol Recovery-funded	3	(15)
	AIDS-funded single family	3	(15)
	Drug/Alcohol Treatment Center	1	(5)

[1] Includes one sharing residence with extended family members.

[2] One mother in California Dept. of Corrections mother-child detention facility.

Family Profiles

Family profiles of the mothers include household composition and information about the children in the home (Table 5).

Household composition. All HIV-positive children lived with their mothers except for one child living in foster care and one child who was recently moved to a pediatric hospice home. The one spouse that resided in the household was dying of AIDS with his wife as the primary caregiver. Thirteen households were comprised of the HIV-positive mother-child dyad, while five included siblings. Number of children in the home ranged from none to three.

HIV-positive children. Each mother in this study had one HIV-positive child. There were 10 male and 10 female HIV-positive children total. Their ages ranged from 5 months to 8 years old. The median age was 3 years 11.5 months; the mean was 3 years 8 months.

Except for two, the HIV-positive children in this study lived with their mothers. Of the two who did not, one shared custody with the foster care placement and the other had been moved to a pediatric hospice. However, both mothers remained actively involved in care and treatment decisions as well as maintaining daily contact with the child or caregivers.

Other children. For 14 of the 20 mothers, their HIV-positive child was their only child. One of those 14 mothers was in the seventh month of her second pregnancy. Five mothers had other children living at home whose ages ranged three to ten years of age, one had other children in foster care. All siblings were HIV-negative.

Table 5

Family Profile

Description (n=20)				n	(%)
Household Composition	Lives alone			1	5)
	With partner/spouse			1	5)
	With HIV+ child only			13	(65)
	With HIV+ child/other children			5	(25)
No. of Children in Home	0[1]			1	(5)
	1			14	(70)
	2			2	(10)
	3			3	(15)
HIV+ Children	Male			10	(50)
	Female			10	(50)
	Age:	Range:	5 mo - 8 yrs		
		Median:	3 yr 11.5 mo		
		Mean:	3 yr 8 mo		
Siblings’ (n = 8)	Male			5	(60)
	Female			3	(40)
	Age:	Range:	3 yr -10 yr		
		Mean:	7 yr		

[1] Includes mother with shared custody arrangement with foster parent.
[2] Includes only siblings living in the home

Health Profiles

The health profiles of the HIV-positive mother and her HIV-positive child were described by: (1) transmission, (2) timing of diagnosis, and (3) general health and treatment, if any. Individual health profiles of each mother-child dyad is presented in Appendix E.

Transmission risk. Table 6 presents the self-reported risk factors for transmission. Ten mothers identified heterosexual contact as the primary mode of transmission; none were aware of their partner's HIV-positive status. Seven mothers reported dual risk factors of injection drug use and sexual contact; one identified injection drug use risk only. One woman was identified as household transmission because she had cared for her mother dying of AIDS and had no other behavior risk factors. During the period of caregiving, the woman was pregnant and delivered a daughter. Another mother with risk behaviors of multiple sex partners, injection drug use, and prison tattoos identified her risk as unknown because she did not believe anyone "really knows how they got it."

Table 6

Number of Mothers by Transmission Risk Factors

Transmission Risk Factors	No. of Mothers (n=20)
Sexual contact only	10
Injection drug use and multiple sex partners	7
Injection drug use only	1
Household transmission	1
Unknown	1

Timing of Diagnosis. All mothers, except three, were diagnosed as a result of their pregnancy (n =7) or their child's HIV diagnosis (n = 10). Of the three who were not, two had been diagnosed before they were pregnant; one mother-child dyad was diagnosed following the husband's AIDS diagnosis.

Table 7

Number of Mothers by Timing of HIV Diagnosis

Timing of Diagnosis	No. of Mothers (n=20)
Before pregnancy	2
During pregnancy:	
<3 months gestation	2
>3 months gestation	5
At birth of child (or <30 days of age)	3
After birth of child :	
30 days - 12 months	4
13 - 24 months	3
25 - 36 months	1

[1] Mother and daughter diagnosed after husband hospitalized with AIDS symptoms.

Mother's general health. Table 8 provides an overview of the mother's characterization of her state of health, symptoms, and treatment, if any.

Table 8

Mothers' Self-Report of Health, Symptoms, and Treatment

Description of Health	No. of Mothers	Symptom ( ) = no. reporting	Treatment ( ) = no. reporting
Extremely poor	1	Renal failure Chronic diarrhea Pancreatitis Peripheral neuropathy	Dialysis Multiple drug therapies
Fair	1	Chronic diarrhea	AZT
Good/ Very good	18	Asymptomatic (17) Clinical markers: [1] T-cells >700 (3) Viral load undetectable (3) Chronic yeast infection (1)	AZT (5) [2] Pentamidine (1) Acupuncture (6) Herbs (7) Meditation (2) Counseling (18)

[1] Not reported by all respondents. [2] One mother currently 7 months pregnant.

Child's general health. Mothers' perceptions of the health of the HIV-positive children are presented in Table 9. Mothers variously characterized their child's health states as extremely poor to excellent. The table below identifies the various health states reported and the children's symptoms associated with each.

Table 9

Mothers' Report of HIV-positive Child's Health, Symptoms, and Treatment

Description of Health	No. of Children	Reported Symptom(s) ( ) = no. reporting	Treatment(s) ( ) = no. reporting
Extremely poor	1	Severe growth & developmental delays CMV infection Comatose; vegetative state >10 days	All treatment terminated. Feeding via gastrostomy tube.
Poor (has 2+ symptoms)	4	Chronic upper respiratory (3) Chronic ear infections (3) Chronic diarrhea (1) T-cell <200 [1] (1) Growth & develop delays (1) Recurrent herpes zoster (1)	AZT (2) Clinical trial (1) No treatment (1)
Fair	1	Chronic ear infections	No treatment.
Good	4	Chronic ear infections (1) Chronic upper respiratory infections (1) Viral load [1]>100,000 (1) No illness >2 years (1)	AZT (2) Septra (1) No treatment (1)
Very good or excellent	10	T-cell [1] 470-1600 (2) Viral load undetectable [1] (1) Chronic ear infections (1) Attention Deficit Disorder (1) No symptoms (8)	No treatment (7) AZT (2) Clinical trial (1)

[1] Clinical markers (i.e. T-cell count or viral loads) not reported for all children.

Summary

In summary, contextual descriptions of the HIV-positive mothers with an HIV-positive child were provided by obtaining personal, family, and health data. The information presented in this section provided a general, composite picture of this sample. The women self-identified ethnic backgrounds of African American, Caucasian, or Hispanic heritages. Average age for mothers was 34 years 3 months and for HIV-positive children 3 years 8 months. One fourth had graduated from high school and nearly half had further education. All mothers but one (employed full-time) relied on financial assistance from various government sources and family; seven of those had been unable to continue their employment due to their illness. Half of the mothers participated in organized religious groups.

For three-fourths of the mothers, their HIV-positive child was their only child. Over half the women were infected by partners or spouse with whom they believed they had a monogamous relationship and most have since divorced or separated as a result.

The women identified heterosexual contact and/or injection drug use as the primary transmission modes of their infection. Most mothers were diagnosed concurrent with their child's diagnosis during early childhood while one mother-child dyad was diagnosed following the spouse's diagnosis with AIDS. The majority of the mothers were asymptomatic and characterized their health as very good or excellent. Mothers reported half of the HIVpositive children as having very good or excellent health although less than half were reported to be asymptomatic. All mothers reported receiving some form of treatment, while half the children were reported as receiving no treatment.

While the focus of this section was to provide an overview of the sample, it is important to view each experience within its individual context. Therefore, personal, family, and health profiles for each mother-child dyad has been provided in the Appendices for reference. The following section reports the categories, related concepts, their properties and dimensions that emerged from the mothers' stories of their experiences.

The Categories

This section will present the major categories that emerged from the mothers' stories of their experience of being HIV-positive and having an HIV-positive child. Through the process of coding, categorizing, and conceptualizing, major categories and related concepts were developed. These categories are: *uncertainty, stigmatization, finding out the diagnosis, effect on family, blame, helplessness, hope, disclosure, and coping*. The emergence of related concepts, their properties and dimensions, provided the contextual description necessary to present these mothers' experiences.

Uncertainty

The feeling of uncertainty emerged as a major category for the mothers in this study. As one mother stated, "The only thing I'm sure of is that I just ain't sure." Related concepts emerged from their stories of feeling uncertain about (a) the course of the illness related to opportunistic/recurrent infections, (b) their management of the child's health, and (c) the child having a sense of his own future. Mothers also shared their strategies for managing these uncertainties, trying to bring some order to their unpredictable life. Table 10 presents the major category of uncertainty, its related concepts, properties, and dimensions.

Table 10

Major Category of *Uncertainty*, Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: UNCERTAINTY

SUBCATEGORY: RELATED TO CHILD

Related Concepts	Properties	Dimensions
Course of Illness (opportunistic & recurrent infections)	duration	short-term - - - - - - long-term
	progression	mild - - - - acute - - - - critical
(of recurrence)	predictability	low - - - - - - - - - - - - - - high
Mother's Management of Child's Illness		
• assessing symptoms • selecting treatment	disease knowledge	low - - - - - - - - - - - - - - high
• providing appropriate care	skill level	low - - - - - - - - - - - - - - high
Disclosure to Child		
• timing	cognition of child	concrete - - - - - - - - abstract
• reaction	from others to child	negative - - - - - - - - -positive
	from child to mother	negative - - - - - - - - -positive
Child Having a Sense of His Future		
• self-identity	level of cognition	concrete - - - - - - - - abstract
• effect of diagnosis & prognosis		
• finding balance between present & future		
Living after Dying		
• mother predeceasing child • child predeceasing mother	predictability or uncertainty	low - - - - - - - - - - - - - - high
• impact on survivor	intensity	mild - - - - - - - - - - - - severe

Course of Illness

All the mothers shared their experiences with the uncertainty of the *course of the*

illness, specifically related to the opportunistic and recurrent chronic infections of their child. The properties and their dimensions of this concept included the uncertainty of (1) knowing the *duration* of infections, (2) predicting the *progression* of each illness, and (3) *the predictability* of their recurrence.

> 31F3.4: So that's just it, you can't tell what's up. You think to yourself : Is this the one? Is this the one that sends her to hospital? Is this the one she doesn't come home from?
>
> 43F3.2: It would be one thing if I could figure out a pattern or something, like clues or hints... I mean, I know I can't, but if I could then, well, then I could know... because sometimes it's not bad, you know. Sometimes it's just 'here's your Septra' and the next check-up, everything's okay. But sometimes, it just goes on and on.
>
> 22F5.0: . . . she's doing okay, no problems [knocks on wood]. But I know what I hear and from what I see that that could change anytime. So when she gets sick with a cold, it's in the back of my mind: will this be the time?

Mother's Management of Child's Illness

Another concept related to uncertainty was the *management of their child's illness*. Mothers described the properties of this concept as the *cognitive knowledge to assess* symptoms so they knew when to seek medical care or provide pain relief, whether they had selected the right treatment, and whether they were providing appropriate care at home. Because of the uncertainty of the disease course, mothers were not sure they had *the proper skills* to provide the proper nursing care for their child.

> 22F5.0: Well, I worry about how I'm supposed to know if they recommend the right or the best treatment for her? That's in the future, but I think about when I see her now, 'Am I missing some signs [symptoms] so that she should get started on treatment?' I've read all I could for now but really what they're saying is if and maybe and so forth. I can't compute in my mind what that really means to me . . . so we just wait and see.

> 43F4.2: So this is how it goes. They are always, always very careful about consents. Well, I sign them, but I don't get it. What am I signing?... They don't know about the treatments and what they do. Well, if they don't know, I guess if nobody knows, how am I supposed to know? How am I supposed to know when to say 'No, not *that one, this one?*'

> 25M1.8: . . . it [HIV] just makes you feel so uncertain about it all. Will I find out tomorrow that what we did today was wrong?

> 35F3.1: I didn't know how to take care of her at home... she couldn't swallow anything and she'd cough all the time. And I'd think she was going to die. I made the decision to put her in the hospice home because I felt like I was her mother, but I wasn't sure if I was doing the right things for her so that if she started to die, would I know how to help her, like not to suffer. She is a sick little girl and she doesn't deserve that [to suffer].

Disclosure to Child

Another concept related to uncertainty was the *disclosure to the child.* Properties included the *timing* of the diagnosis related to the child's level of cognitive development. Mothers were concerned about the ability of the child to understand the physiological and psychological implications of having HIV and to keep the diagnosis secret. Properties related to the concept of disclosure to the child also included *reactions from others and reactions from the child to the mother.*

> 43F4.2: Oh yes, she has to know [the diagnosis] but it's a question about when is the right time . . . she has to know when to keep it a secret.

> 36M7.2: I expect the day's coming where he'll ask me how he got HIV and when, I tell him, I expect that some days he'll hate me. Especially if other people hate him for having [HIV infection].

Child Having A Sense of the Future

This concept grew from four mothers expressing concerns that their HIV-positive children would not have a *sense of their own future,* that they would lack vision of where

they fit into the future. Mothers felt that an important part of the child's development was the child being able to see a place for themself in the future. However, the mothers also felt so much about HIV is negative, they were uncertain that the HIV-positive children would be able to envision themselves as having a future.

> 36M7.2: If they could stay at a good level academically, that'll keep them going far, that'll let them go far . . . that'll help them be whatever they want to be when they get older. But for now, you don't stop them [from thinking about future] . . . I'm afraid that if she can't see herself, feel like she's a part [of the future], that she won't live. I'm not sure she has that. They [children] have to see where they fit, get a sense of having a future. But with AIDS, I'm not sure she has that.
>
> 32M4.9: Part of it is that he needs to feel he's somebody besides somebody with HIV. He has to get a feel for himself in his own future or he will grow up to be somebody dying of AIDS. I don't know how to know this about him, but I think it's important for him to feel this even if he gets AIDS.
>
> 34M4.10: Well it keeps you alive living for that [the future], that's for sure. With AIDS, or really before AIDS, with HIV you can only figure out where you're going to fit in in the future if you concentrate on making it today . . . so when he hears what HIV means, it will mean something different than 'damn, I'm dead now' because he sees himself married or in college or whatever.
>
> 35F3.1: It's that vision that keeps you going, you gotta have it. I couldn't give it to her because she has, like, dementia. You know how you sense you belong somewhere, it's kind of like that, but out of body in a way. When you feel like you fit [in the future], like you have a place there, then you're a person, not someone who's dying whose got no future . . . The question is: How does a child get that [feeling] when she finds out she's got a disease like AIDS?

Living After Dying

From the mothers' stories emerged the experience of uncertainty as to whether the mother would predecease her child or her child predecease her. The concept name was

taken from the in vivo code of one mother who discussed the issues facing HIV-positive mothers whose child is infected also.

> 35F3.1: I knew she would go first because she was always sickly from the very beginning. But I wondered what would happen if she was my only child and really my reason for living. I have my other kids, thank God, because I wonder if I would have a reason to live.
>
> That's a big thing, really. We stay alive because who will take in a child with this infection? We don't know so we stay alive. But you know, there's living after dying no matter who dies first. Either your child lives after you die and you hope there's someone to love them, or your child dies and you're stuck living. Our group calls that 'living after dying.' No matter who dies, someone's left living.

Strategies to Manage Uncertainty

In their experience with the uncertainties they faced, mothers also shared the strategies they used to manage them. The strategies were organized into: management of the illness, the child's health, and the awareness of the future. Table 11 presents these strategies and how they were operationalized.

Table 11

Strategies Used by Mothers to Manage Uncertainty

Strategy	Action
Management of Course of Illness	
• overprotectiveness	"watched him every minute"
• overreacted	"called the doctor or the hospital all the time, until I could start to figure some of it out"
• filtered information	"started only listening to what I needed because I found out a lot of stuff that scared me even worse"

Management of Child's Illness

• seek information from multiple sources	"started going to the WORLD University to learn more about treatments and results of clinical trials" "I talked to people at the Center and got hold of the manual that listed all the clinical trial results"
• manage environment	"the school will have to know so she can get her AZT at lunchtime" "I would have to make sure that they [day care] uses universal precautions, you have to think of everybody"
• use outside agency	"a lot of kids die at home, but I made the decision to put her in the hospice home because she was such a sick little girl"

Management of Disclosure to the Child

• timing the disclosure	"when she's old enough to understand, maybe ten"
• not telling anyone	"I wouldn't want it to get around at the school, because I wouldn't want her to find out like that"
• selective disclosure	

Management of Child's Sense of the Future

• integrate future-oriented thinking with present-oriented actions	"take one day at a time with short-term future goals like going to Disneyland" "you don't stop them from [thinking about the future]" "have short-term goals that can stretch into longer goals"

Management of Living after Dying

• arrange legal custody	" It's all arranged. [daughter] will go to Texas where my friend will take care of her if I can't."
• seek support before and after child's death	" We [HIV+ mothers] need to get counseling, see a therapist, before the child dies and after child's death, to help us get through it. It's too late after he dies."

Stigmatization

All mothers in the current study reported stigmatization they attributed to their HIV infection. From their stories emerged concepts related to the phenomenon of stigmatization. Table 12 presents the major category of *stigmatization* and the related concepts of *reaction from others* and *experiencing triple stigma,* their properties and dimensions.

Table 12

Major Category of *Stigmatization*, Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: STIGMATIZATION

SUBCATEGORY: OF HIV+ MOTHER WITH HIV+ CHILD

Related Concept	Properties	Dimensions
Reaction from Others	intensity	low - - - - - - - - - - - - - -high
• overt behaviors	quality of interaction	negative - - - - - - - - -positive
• covert/perceived behaviors	space (geographic)	distant - - - - - - - - - - - - near
	frequency	never - - - - - - - - - - - - often
	behaviors	covert - - - - - - - - - - - - -overt
Triple Stigma		
• HIV infection as lethal,	attribution	discriminate - - indiscriminate
• contagious disease	degree of fear (of contagion)	mild - - - - - - - - - - - - severe
• presumption by others of maternal drug and high-risk sexual behaviors	self-responsibility (for infection)	low - - - - - - - - - - - - - - high
• infecting innocent victims	risk awareness (by mother)	not aware - - - - - - - - -aware

Reactions from Others

Mothers reported being stigmatized that ranged from relationships with people

both close and distant to them. They identified close relationships as parents, grandmother, and even their own siblings. Distant relationships included those with whom the mother did not have direct contact, but whose actions promoted stigmatization, such as political or religious leaders, even their own relatives, who promote AIDS as a punishment or deserved by the recipient.

> 41F1.1: . . . so when she [grandmother] found out, she put us out. Just out on the street, just like that. No questions, nothing ... she already had it in her mind, she already knew ... that you don't get AIDS unless you asked for it.

> 31F1.4 (In 1994): Several weeks ago I was invited to this group as a guest speaker, I guessed they heard about me doing public speaking. So I went and there was another minister to speak also. So he went before me and it turns out that I was supposed to be, I was the one, I was the sinner. Like I was the example of what happens to sinners. HIV was a punishment for my sins. I never did get to speak.

While mothers readily identified overt behaviors of stigmatization, some also reported covert behaviors they attributed to stigma of HIV disease. Their perception of covert stigma was based on the behavior of others when they (a) maintained a physical distance between the mother and themselves, (b) acted uncomfortably despite stating that HIV was not an issue, and (c) presumed that the mother had a previous lifestyle of drug use and prostitution for drugs.

Experiencing Triple Stigma

Almost all the mothers identified the general stigma of HIV/AIDS as being a lethal, contagious disease. Fear of contagion increased the stigma of HIV/AIDS.

> 37M4.6 (in 1995): ... he had [scraped] himself on a shell and I was going to get the first aid kit . . Well, she [step-mother] ran out saying, 'No, no, no! You can't bring him in here [inside house]!' She made me wash himself outside with the hose, and then ran in the

> house and got paper towels, a band-aid, and a plastic bag. She made me clean him off outside and put the Band-Aid on, and throw everything in the plastic bag. And then had me hand carry it to the garbage can.

Mothers who did not have risk behaviors of injection drug use or multiple sexual partners felt they suffered that stigma of those behaviors anyway. They reported this experience especially in contacts with health care professionals.

> 36M3.2: I know when they [clinic physicians or nurses] start getting all personalized about how did I get the virus, I know they're looking to see if I deserved it [being infected]... it makes a difference to them, you know.

> 22F5.0: It hurts that when people look at you that they look right away down at your arms.

Several mothers who reported their transmission risk behaviors related to their injection drug use (sharing needles and multiple sex partners) also believed they were stigmatized because they had infected their child. However, mothers infected through heterosexual contact reported feeling stigmatized for that reason also.

> 31F3.4: I know I gave it to my baby. I know my baby don't serve to have it [HIV infection]. Nobody deserves that. But I don't deserve it either. Because I am the reason for my baby going to die but it's not like I knowingly infected her, like I knew and I went ahead and not caring if I gave it to her ... I feel like people think that, that I knowingly gave it to her.

> 41F1.1: Sometimes they [others] act full of pity [toward child] like 'poor baby, never had a chance.' She *is* (emphasis) an innocent victim of HIV, but so am I. The fact that he already knew and he gave it to me and let me get pregnant, that was devastating to me . . . But people only see that my baby has it because of me, but I'm innocent, too.

<u>Strategies to Manage Stigma</u>

Mothers reported managing stigma by *suppressing* (their diagnosis) and/or *passing* (attributing any HIV-related condition or circumstance to non-HIV sources). Table 13

reflects these strategies and how they were operationalized by the mothers.

Table 13

Strategies Used by HIV-positive Mothers to Manage Stigma

Strategy	Actions
Suppression of Diagnosis	"so I don't tell [other] and then I don't have to go into why I'm not to blame for [being infected]" "I don't offer them the diagnosis"
Passing	"I just tell them [the recurrent PCP pneumonias] are from having weak lungs from my asthma" "If I care [about the person] I just let it slip I got infected from a blood transfusion so it's like anybody could have gotten it"

Summary

All mothers reported experiences of being stigmatized as actual or perceived. Experiences ranged from people with whom mothers had close relationships to those with whom they had distant relationships.

The concept of *experiencing triple stigma* emerged from the mothers who described feeling stigmatized from all directions. Mothers identified feeling stigmatized due at least one of the following: (a) because HIV is seen as contagious and lethal, (b) because of the presumption that they must have used drugs or been sexually promiscuous, and (c) because they infected an innocent person (their own child). Four mothers reported stigmatization due to all three of those circumstances.

Mothers used two primary strategies to manage stigma. One strategy was to *suppress the diagnosis,* that is, not voluntarily disclosing their HIV diagnosis. Some mothers controlled feeling stigmatized by *passing* themselves as normal, that is, attributing

HIV-related conditions to non-HIV causations to reduce the stigmatization of being contagious with a fatal disease.

Finding Out the Diagnosis

The category, *finding out the diagnosis,* emerged as a major part of these mothers' experience. The category reflects the mothers' experience in being diagnosed with a lethal, highly-stigmatized disease oftentimes made during the pregnancy or after the child's diagnosis. Mothers were forced to face issues of death and dying at a time generally associated with life and living.

Their experience and the challenges they faced were related to the *timing of the diagnosis:* before becoming pregnant, during the pregnancy, or during the first years of their child's life. At a time when mothers were suddenly faced with critical decisions for themselves regarding terminating their pregnancy and/or making treatment decisions, they were confronted with their own and their child's mortality. *Emotional reactions* of shock, denial, anger, and depression dominated their lives. *Behavioral responses* ranged from depression to an attempt at suicide.

From the mothers' experience emerged the major category *of finding out the diagnosis* and the subcategories of *reactions to the diagnosis* and *timing of the diagnosis.* Related concepts for both subcategories are presented in Tables 14 and 15, along with their properties and dimensions.

Table 14

Major Category of *Finding Out the Diagnosis*, Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: FINDING OUT THE DIAGNOSIS		
SUBCATEGORY: TIMING OF DIAGNOSIS		
Related Concepts	Properties	Dimensions
Diagnosis before pregnancy • family planning	decision to bear children	no - - - - - unsure - - - - - yes
Diagnosis during pregnancy • continuation of pregnancy	timing	early - - - - - - - - - - - - - late pregnancy pregnancy
Diagnosis after birth		
• realization of dual impact	intensity	mild - - - - - - - - - - - - severe
• impact on family	reaction	negative - - - - - - - - positive
• impact on lifestyle	impact	no change - - - - - - - - change
• treatment	state of illness	asymptomatic - - - - - - AIDS

Timing of Diagnosis

The mothers shared their experience from the temporal aspects of being diagnosed with HIV before they became pregnant, during their pregnancy, or concurrent with their child's diagnosis (either at the time of birth or during early childhood). This section presents their experiences of being diagnosed within the context of those time frames.

Maternal diagnosis before pregnancy. Two mothers reported knowing their HIV diagnosis prior to becoming pregnant. The mothers had been tested although they were asymptomatic: one tested "just for fun" and the other at the recommendation of her doctor due to lifestyle risk factors.

All mothers, whether diagnosed independently or concurrently with their children's

diagnoses, discussed the major impact of being diagnosed at this time as their belief that they would neither have children nor become pregnant in the future. Even mothers who had knowledge of the reduced perinatal transmission rate with antiretroviral therapy during pregnancy also stated they believed they would not risk pregnancy. However, two mothers had an additional pregnancy after having their child diagnosed with HIV; one mother was in her seventh month of pregnancy at the time of the interview and the other mother delivered an HIV-negative child.

Maternal diagnosis during pregnancy . Seven mothers were diagnosed during their pregnancy: two in the first trimester, five at six months or later. The two mothers who knew of their diagnosis prior to becoming pregnant had their pregnancies confirmed in the first trimester.

Two mothers were diagnosed through routine testing performed as part of the prenatal care regimen. Five mothers were diagnosed through testing recommended by health care providers as a result of self-identified maternal HIV risk factors of injection drug use or partner with injection drugs.

All pregnant mothers in their third month of pregnancy faced the decision of whether to continue their pregnancy. They identified three factors influencing their decision: the advanced state of the pregnancy; the pressure from medical staff, and their religious or moral beliefs.

> 42F0.5: And so they told me that there was an 80 percent chance my child would be positive. But I was already six months pregnant, so I couldn't terminate the pregnancy.
>
> Q: If you had known earlier, would you have terminated your pregnancy?
>
> 42F.05: Yes, I think I would have.

Moreover, mothers reported feeling pressured by doctors to terminate their pregnancy. 31F1.4, diagnosed at 3-1/2 months pregnancy in Texas, and 45M4.0, diagnosed at 3 months pregnancy in Oakland, California shared their experiences.

> 31F1.4: The doctor gave me 24 hours to decide on abortion . . . They said if I kept the baby I would only live six months and the baby would come out severely deformed and all. They told everyone the same thing and the same choice for everyone . . . There was people in there left and right getting abortions. They just didn't want ANY AIDS babies.

> 45M4.0: . . . they [doctors] really sat down and talked to me and told me what it was, how it would affect my fetus, my child. They kind of strongly suggested that I have an abortion. They wasn't trying to *tell* me what to do, but they was saying 'You don't want to bring a child into this world that got AIDS. He's going to be sick all the time. I mean, he might not live to be a year.'

Despite the early nature of their pregnancy, some mothers attributed their decisions regarding terminating their pregnancy to their moral or religious beliefs.

> 42F.5: I believe that for an abortion there has to be a good reason. I didn't have that reason because this wasn't a rape or incest and so there wasn't a reason to have an abortion.

> 45M4.0: So he [doctor] sat down with me and told me that I was HIV-positive. Course, I didn't know what that was. I said, 'What is that?' and he said, 'Well, that's the virus that causes AIDS and you could die from it.' ... then it really came to whether to keep the baby or not, because I was three months along. Did I want to terminate the pregnancy? I might have if I wasn't in church, but as far as being in church and stuff, I couldn't do it.

All mothers were asked whether they would consider abortion if the state of their pregnancies did not preclude abortion as an option. Seven would not have considered abortion and two were not sure. Eleven reported that they would, or probably would have, terminated their pregnancy.

Maternal diagnosis concurrent with or following child's diagnosis. More than half

the mothers were diagnosed after their child had been diagnosed with HIV. Of those, three were diagnosed in the newborn period, usually within 30 days of the child's birth. One mother was tested for HIV following the baby's positive gonorrhea test and the other two due to the infant's small size for gestational age and/or premature delivery coupled with their history of injection drug use. Of the eight children diagnosed during early childhood, most of the mothers lacked identifiable risk factors so that HIV testing of the child was performed after exhaustive diagnostic attempts failed to determine the source of the child's chronic or acute illness. All eight mothers who had a history of injection drug use had previously tested negative for HIV at least once. In all cases, the mothers' diagnoses quickly followed the children's diagnoses.

> 35F1.1: Looking back, when she had spinal meningitis when Mxx was two months old, that was probably the first sign of her AIDS. She had knots on the back of her ears, but I didn't know. I didn't know ... The doctor thought it was probably leukemia. I thought it was sickle cell because sickle cell trait runs in our family. The therapist at the Developmental Center suggested an AIDS test. I was shocked [at the suggestion].
>
> 30F8.0: She was about 18 months and she had PCP pneumonia three times and they couldn't figure out why . . . They didn't think to test her because I was a heterosexual woman, so they didn't think to test me . . . I had swollen lymph glands . . . for about two years and they just said, 'You're one person who gets lots of colds and flus . . . they probably won't go down.' So one doctor from Mt. Zion got real smart. He said, 'You know what? Your mother died from AIDS. You took care of her. Why don't we go test this baby for that?'

These mothers identified issues that they faced immediately after the child's diagnosis: implication of the diagnosis for themselves; impact on relationships or lifestyle; and decisions regarding treatment. Three mothers described the dual impact of their child's HIV-positive diagnosis; that is, their child not only had a terminal illness, but they

had it as well.

> 35F3.1: . . . During that time [of the HIV test], Mxx was nine months old and weighed 14 pounds ... They told me she was positive. Because I knew she had never had a blood transfusion or anything, I knew I had to have given it to her. So, in a sense, they were telling me that I had it.

> 30F8.0: That [suggestion to HIV test the child] blew my mind. My child ain't had no intercourse . . . ain't no drug user . . . ain't had no blood transfusion. Why you want to do all that? I thought. But I let them do it and then it came back ... and then they said, 'Let's test you.'

> 36M3.2: I had always taken HIV tests before and I never had it. I had never shot drugs, but I did hustle myself for crack. So when my baby was born too early. . . he was only two pounds, I figured it was from doing crack, not because of HIV. So I was shocked for my baby and for me.

Moreover, eight of the eleven mothers in this group had been infected by husbands or partners who knew, but did not disclose to the women, their HIV-positive status. The impact on relationships was immediate as mothers described their reactions to these partners or spouses as shock at learning the partner's positive status and risk behaviors (generally injection drug use and/or sexual behavior); as anger that partners did not reveal their infection; and as hate for the partner for causing the mother to be the vector of their child's infection. All but one of the women with partners or spouses in this group have subsequently separated or divorced.

The four mothers whose risk factors were injection drug use or sexual behaviors related to drug use were immediately faced with lifestyle decisions. These mothers had to enter a recovery program if they wanted to have eventual custody of their child. By the time of the children's discharge following their birth, none of the mothers were allowed custody so that all the children were placed with a relative or foster care. All mothers have

regained custody of their HIV-positive child although some of their other children remain in the custody of other family members or in foster care homes.

One mother became infected while caring for her mother who ultimately died of AIDS. Unaware of the diagnosis, the daughter cared for her mother during her pregnancy and after her child's birth. Subsequently, the daughter and her child were diagnosed almost two years after the mother's death, after the child's repeated pneumocystis carinii pneumonia infections. The father was HIV-negative. Married at the time of the interview, they were separated and planned to divorce due to the emotional and financial stresses of a family living with AIDS.

> 30F8.0: I'm still married but separated . . . [It's] all the stress of trying to deal with having a family infected. He wants to have a life and we really can't have a life *he* (emphasis) wants... You know, she was always sick, we were always sick. So that was in and out of the hospital constantly.
>
> He had to take off work and so . . . he lost a couple of jobs. So he really had a lot to got through, so we figured it might be easier for him to get his life situated and get started if he was in another household. And that way me and my daughter could get full benefits for ourselves if we're not considered still married to him. Cause see, still being married to him cut us off of a lot of our benefits. . . just one of [daughter's] medicines cost a thousand dollars and she's taking like four different medicines everyday plus she goes in for IV gamma globulin. That's *every* (emphasis) month. Who's going to afford that?... My AZT is four hundred something dollars. That doesn't include all the other fifteen tablets I'm taking.

While all mothers in the study eventually faced treatment decisions for themselves and their children, mothers identified their dilemma as whether or not to treat their children and/or themselves. If yes, then what treatment? They reported their decisions to receive treatment as strongly influenced by their physician's advice.

> 45F6.6: She [HIV-positive daughter] is on AZT right now . . . They

> [doctors] just wanted to try this first to see how this would work for her and then add another one and then another one. That's how the doctor wants to do it.

Decisions not to receive treatment were primarily attributed to fears surrounding current drug therapies.

> 31F1.4: For myself, I would take the drugs, but never AZT again! I've heard about acupuncture and am about ready to try it ... But for my baby, I would never, never give her anything toxic like the drugs they have. I don't think they know what they'll do to the children.

> 25M1.8: I think we should just wait and see. Maybe the drugs they have out could help him, but could they make him worse too? I'm hoping he'll get better and the [T-cell] counts will come up without it. If he dies anyway, how would I know if it was from full blown AIDS or those drugs?

Reaction to Diagnosis

All mothers were willing to share their emotional and physical reactions to finding out their HIV-positive diagnosis. These reactions occurred independent of the timing of the diagnosis. Table 15 presents the major category and related concepts.

Table 15

Major Category of *Finding Out the Diagnosis*, Subcategory of *Reaction to Diagnosis*, Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: FINDING OUT THE DIAGNOSIS

SUBCATEGORY: REACTION TO DIAGNOSIS

Related Concepts	Properties	Dimensions
Emotional Reactions		
• diagnostic shock	intensity	mild - - - - - - - - - - - -severe
• denial	extent	acceptance - - - - - - - - denial
• depression	intensity	mild - - - - - - - - - - - -severe
Behavioral Reactions		
• depression	intensity	mild - - - - - - - - - - - -severe
• drug/ETOH use	frequency	decreased - - - - - - increased

Emotional reactions. Emotional reactions ranged from diagnostic shock to severe depression. Table 16 presents the descriptions reported by the mothers.

Table 16

Mothers' Descriptions of Emotional Reactions to *Finding Out the Diagnosis*.

Reaction	Mothers' Description of Emotions
diagnostic shock	• feeling overwhelmed • feeling devastated
denial	• disbelief • re-tested child
depression	• crying • unable to concentrate • unable to talk about it • 'not caring' about HIV-positive child or other children

Diagnostic shock. Only one mother, diagnosed through routine testing in her sixth month of pregnancy, did not report being shocked at her diagnosis. Even mothers who had known risk factors described their reactions as feelings of shock and being overwhelmed or devastated by the diagnosis.

> 31F1.4 (diagnosed before pregnancy): . . . Me and another girlfriend went in and got tested . . . just for fun. We were fooling around and just went in the [college] health center and got tested. I was shocked, really shocked. I tested positive. It wasn't like I was whoring around or nothing. So I was really shocked.

> 45M4.0 (diagnosed at 3 months pregnant): The doctor said I was HIV positive, 'You could die from it.' I thought HIV was something that was bad, but I would just take something for it and be cured. After I read the literature he [the doctor] gave me to take home and read, it was too overwhelming, it was too much.

> 36M3.2 (diagnosed one week after birth): I had always taken HIV tests before and I never had it. I had never shot drugs, but I did hustle myself for

> crack . . . But when they told me, I was shocked. I was shocked beyond words.

Denial. Two mothers, diagnosed following their child's diagnosis, reported feeling denial after the initial HIV diagnosis.

> 45F6.6: Yeah, well, the doctor just told me and then they sent me to a lady to talk to. I was like in denial at the time and I was just thinking maybe they made a mistake. Then I had her [daughter] tested again [pause] and I found out again she was positive.

> 37M4.6: I have a real hard time looking that far into the future because since the diagnosis and since my acceptance with the diagnosis, cause in the first two years I was in denial . . . It couldn't be me, it couldn't be me. It was hard to accept that someday I was going to die sooner than I thought or had expected.

Depression. In the immediate period Following their child's or their own diagnosis, sixteen mothers (many of whom had also expressed feeling devastated and overwhelmed by the diagnosis) reported that they spent extended periods of time crying and were unable or barely able to function in daily living activities. Eight reported they were unable to even speak the diagnosis aloud.

> 30F8.0: When I found out about my daughter, it hit me. I didn't do much of anything but sit around and cry. I cried so much. I'd just hold her and cry. There's nothing I could do but hold her and cry, cry, cry. I could barely think straight.

> 42F0.5: During my pregnancy I was having a lot of pain in my lymph nodes . . . and me taking all kinds of antibiotics . . . and blood tests to see if it was something in my blood . . . So the lady said, 'Did you ever have an HIV test?' And I said no, because I don't use drugs or nothing like that. And then when I took it, I found out I was positive . . . I cried for about a whole month straight. I couldn't tell nobody nothing. I would just cry when I would talk about it. It's been devastating.

> 34M4.10: It didn't matter I was still doing [drugs]. I'd just lay around feeling bad and couldn't decide what was happening. I couldn't eat or think

> or figure out what to do. I just thought, 'Damn, my life's over with now.' It was like I was too depressed to even care about my baby.

Behavioral reactions. As with their emotional reactions to the diagnosis, the mothers' behavioral reactions occurred independently of the timing of the diagnosis. Two areas in which behavioral responses were described were related to depression and drug/alcohol use. Table 17 presents the behaviors reported by the mothers.

Table 17

Mothers' Descriptions of *Behavioral Reactions* to Finding Out the Diagnosis

Reaction	Mothers' Description of Behaviors
depression	• lethargy • decreased/loss of appetite • unable to perform routine activities • attempted suicide
drug and/or alcohol related behaviors	• no change in drug/alcohol use • entered recovery program • relapsed into previous drug/alcohol use behaviors • increased alcohol intake

Depression. Nearly three-fourths of the mothers reported mild to severe behavioral symptoms of depression. Behavioral symptoms ranged from the inability to get out of bed to feeling too tired to participate in daily activities of living or care for their children to one mother's attempted suicide.

> 36M7.2: I spent so much time crying . . . some days I would wake up and not even get out of bed. I was just heartbroken. (crying) It's just so hard.

> 35F3.11: I didn't care about my other kids at home. I was in such despair like. It was so I couldn't get up - I didn't even want to get up.

> 45M4.0: It [the diagnosis] was just too much. It was just too much. It was too much to handle . . . After reading the literature he [doctor] gave me to take home and read, it was too overwhelming, it was too much. [Her sister] had taken the kids for the weekend to give me a rest, so then I didn't really think about the baby I was carrying. I just took a bunch of sleeping pills and tried to kill myself. And a friend found me just in time. It was just too much to handle.

Drug and/or alcohol-related behaviors. Six mothers had reported injection drug use as potential risk factors. Two mothers had already completed recovery programs before their pregnancy. Of the four mothers that entered drug and/or alcohol recovery programs following their child's birth, one mother entered in the postpartum period, two entered after the child's first birthday, and one after the child's second birthday. All four mothers cited their HIV-positive child as their primary motivator to enter, continue, and/or return to their recovery programs. Two of these mothers reported relapses and attributed it to the stress of learning the dual infection.

> 35M3.6: She [child's previous foster mother] doesn't like the fact that I relapsed. She said, 'Txxx is your priority.' That's easy for her to say. Now you try to be in my shoes. First of all, finding out I'm HIV, [being told] in the street . . . I was insecure about being a parent in the first place and then be a parent of a baby that's medically fragile. It was scary. It was like really, really scary.

> 36M3.2: Well, I wasn't going to get custody after my baby was born. I knew that. But my sister said she would take the baby, even not knowing nothing about medicines or HIV care. She said she would help my baby but not me until I got into recovery. That took a couple years. I thought that by then my baby would die, but he didn't so I figured he needed me.

One mother described her experience of drinking heavily following the diagnosis of her child and herself.

> 35F3.11: I went through a lot of self-destructive things. So I just started drinking and it took about three months of putting down

> Jack Daniels that I finally took a good look at myself and decided I was the only mother of my other kids and I needed to be a mother to them.

Summary

In summary, two mothers were diagnosed prior to their pregnancy with eight diagnosed during their pregnancy and ten subsequent to their child's diagnosis. Two mothers reported pregnancies, characterized as unplanned, after their last child had been diagnosed with HIV infection.

Eight mothers discussed their decision of whether to terminate their pregnancy. Mothers diagnosed during their pregnancies identified primary factors that influenced their decision whether to continue their pregnancy to term: (1) the advanced state of the pregnancy and (2) their own moral and spiritual beliefs. Four mothers reported feeling pressured by their physician(s) to terminate their pregnancy.

Despite the time of diagnosis or the mode of transmission, all but one mother reported being shocked at the diagnosis. The majority of mothers variously described feelings of shock, devastation, and/or being overwhelmed by their diagnosis. Only one mother reported denial of the initial diagnosis and had her child retested.

Four-fifths of the mothers reported emotional characteristics of depression following their HIV diagnosis. Depression was characterized by the mothers' crying for extended periods of time and their inability to concentrate or talk about their diagnosis. One-fourth of all mothers reported behavioral characteristics of depression as well: lethargy, decreased/loss of appetite, and/or inability to perform routine care for self and/or children. One mother reported attempting suicide.

The other major behavioral responses to the diagnosis were related to drug and/or alcohol use. One mother with no history of excessive alcohol intake reported she drank heavily for three months following the diagnosis. Four mothers entered residential recovery programs; two continue in their programs while two have completed theirs.

Effect on Family

The stories of the mothers' experiences with family varied according to the level of their relationship. Each level had its own set of dynamics that influenced whether the relationship was enhanced, maintained, changed, worsened, or ended as the result of the mother's HIV infection. These levels of family: the individual (mother), mother-child, mother-spouse/partner, extended, and distant family relationships emerged as subcategories. Related concepts reflected the effects of the maternal-child HIV diagnosis within each subcategory.

Mother: Self-Identity

All the mothers expressed sadness at some aspect of their maternal role. Mothers of only children discussed their difficulty in establishing an identity, while mothers with other children struggled to maintain their maternal identity. Several mothers wanted to preserve their identity as the mother should they predecease their child. Grounded in these experiences, three concepts related to the major category of *effect on family* emerged: *establishing, maintaining,* and *preserving the identity as mother.* These concepts, their properties and dimensions, are presented in the following table.

Table 18

Major Category of *Effect on Family* and Subcategory: *Mother: Self-Identity*, and Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: EFFECT ON FAMILY		
SUBCATEGORY: MOTHER: SELF-IDENTITY		
Related Concepts	**Properties**	**Dimensions**
Establishing Identity	maternal behaviors/ interactions	restricted- - - - - - - - unrestricted
Maintaining Identity	health level of caregiving	asymptomatic- - - - - - - - - AIDS low - - - - - - - - - - - - - - - - high
Preserving Identity	longevity (maternal)	less- - - - - - - - - - - - - - - greater than child than child

Establishing identity as mother. All mothers expressed the difficulty in establishing or maintaining their role as mother at some period during their HIV illness. As reported, fifteen children were the only children in the family. One-fourth of their mothers were 39 to 41 years old at the time of diagnosis. One mother said she would have ended the pregnancy if diagnosed earlier. However, these mothers felt they had no chance *to establish an identity as a mother,* since they believed the likelihood of mother or child surviving together was extremely poor. They reported struggling with establishing a maternal identity believing that they would never have more than several years with the child.

Other mothers, whose ages ranged between 20 and 35 years at the time of their diagnosis, had looked forward to beginning their family. All had planned to bear other children. They struggled with accepting their role of 'mother with a dying child' and

the loss of their identity as a mother.

> 37M4.6: When I got pregnant at the age of 32, it was miraculous. They said my chance of conceiving were 2%. If I were to get pregnant, my chance of having the baby were 6% . . . It was hard when they made me stop pumping for milk. I started giving him formula, that was hard because just at the age he was being able to suck on my breast, that's when they asked me to stop breastfeeding him.
>
> [Breastfeeding] was very important. I've always wanted to be a mother and have a family. (crying) That was important to me. The fact that this man had given this to me and didn't tell me with my first and only child was devastating.

Maintaining identity as mother. Mothers who had other children struggled more with trying *to maintain their identity as a mother.* They wanted to keep things as normal as possible, until their health or their child's health required them to alter their family routine. Mothers wanted to maintain their identity as a 'mother,' rather than 'the person with AIDS.' To do so, mothers reported they either denied (subconscious blocking out of emotional experience) or suppressed (conscious decision to delay facing an unwanted conflict) their diagnosis.

> 36M7.2: I have to pretend like I don't have it. That way, nothing changes right now. There's no sense in changing anything until we have to. We're both feeling good so I just watch out for everybody. I mean, it's in the back of my mind right now but there's no sense in bringing out now.

> 31F1.4: I pretend I don't have it. I ignore it and just put it out of my mind and as long as I'm feeling okay, I don't have to think about it. I don't have it. I just never think that I have it.

Preserving identity as mother. One issue facing mothers was the uncertainty of predeceasing their child. Half the mothers felt that they would probably die before their child and that the child would not remember them. Because someone else would raise

them, there would be no *preservation of their identity as mother* as the person filling the mother role would likely assume that identity.

> 31F1.4: I worry, well, I'm afraid that my daughter won't remember me. Like with my mom, I have a snapshot of her and I use that to comfort me sometimes. So I need something like that for my daughter, even if she doesn't live long after I go first . . . I want her to have something positive of me, so maybe I'll tape one of my presentations.

> 32M4.9: So you do the best you can and hope that something of you stays with your child after you're long gone. That's part of the sadness, that you only get one child and you're probably going to die when he's young. He can never say, like, that's my mom when he sees my picture or something or people talk about me. Someone else will be his mom and that's okay, but I should have had the chance, too.

The Mother-Child Relationship

More than half described their relationship with their child as special because of the bond formed by their dual HIV infection. Mothers who were asymptomatic were more likely to stress qualities of the relationship as supportive, providing affection, and giving the mother a reason to live.

> 22F5.0: I have to stay alive for my daughter. She has no chance without me. When we return to my family, I don't know how it'll be for sure, but we'll help each other ... Right now she's a perfect little girl, she helps me with her father [dying of AIDS] and she'll need me; we'll need each other when he dies.

However, mothers who had HIV-related symptoms or whose child was symptomatic emphasized the caregiving aspects of the relationship. They reported the need for respite but, at the same time, were hesitant to leave their child.

Effect on Family Relationships

Mothers described the effect of being HIV-positive on the immediate family from four perspectives: the mother-spouse/partner relationship, the immediate family relationship, the extended family relationship, and the distant family relationship. *Immediate family* members were generally the partner or spouse and children. *Extended family* included maternal grandparents and parents, in-laws, mothers' siblings, and any other relatives who participated in family events regularly (e.g., birthdays, holidays). Most often they were aunts, uncles, even second or third cousins. *Distant family* referred to relatives living in other parts of the state or country with whom they had less frequent, more formal contact (e.g., weddings, Christmas card exchange).

The following section presents findings on the effect on the family by identified subcategories of. mother-spouse/partner relationships (married, single with partner at diagnosis, and single with no regular partner); immediate family; extended family, and distant family. Related concepts, their properties and dimensions, will be presented.

Married mothers. Three of the four mothers married at the time of diagnosis were now separated or divorced. Two mothers attributed the dissolution of their marriage to the husband's HIV-positive status of which they had been aware. One mother felt her relationship had been enhanced by the family's illness. Her love for her husband had always been strong, but was now 'fuller' because of the circumstances of the family's infection. Her husband's recent diagnosis of AIDS was their first experience with HIV disease, he was dying at home, and had been a 'good husband' to her. Table 19 presents the subcategory of Mother-Spouse/Partner Relationships, its concepts and dimensions.

Table 19

Major Category of *Effect on Family*, Subcategory of *Mother-Spouse/partner Relationship*, Related Concepts, Properties and Dimensions

MAJOR CATEGORY: EFFECT ON FAMILY

SUBCATEGORY: MOTHER-SPOUSE/PARTNER RELATIONSHIP

Related Concepts	Properties	Dimensions
Relationship Enhanced	quality (before diagnosis)	supportive - - - nonsupportive
	partner HIV+ status	known - - - - - - - - - not known
	partner health status	asymptomatic - - - - - - - AIDS
Relationship Maintained	source of transmission	other - - - - - - - - - - - - spouse
	quality (before diagnosis)	supportive - - - nonsupportive
	duration of association	short - - - - - - - - - - - - - - long
Relationship Ended	source of transmission	other - - - - - - - - - - - - spouse
	blaming the other	by spouse - - - - - - by mother
	financial stress	low - - - - - - - - - - - - - - - high
	risk behaviors	continued - - - - - - - - - ended

One mother, infected when caring for her dying mother, cited financial need compounded by the spouse's stress in coping with the effect of the disease on his family as the reason for separating.

> 30F8.0: He had to take off work jobs. . . so he lost a couple of jobs. . . . still being married to him cut . . . benefits . . . one [prescription] costs a thousand dollars a month . . . That doesn't include all the other fifteen tablets I'm taking.
>
> I'm still married but we're separated. And a lot of it is due to the fact that he wants another child and he knows I can't give it to him. And all the stress of trying to deal with having a family infected. His first child, his only child, has the virus. He wants to have a life and we really can't have a life *he* wants because he's still young too.

Single with a regular partner at the time of diagnosis. Of these nine mothers, six reported HIV-positive partners as their only risk factor, while three participated in high risk sex behaviors and/or injection drug use. For those three with multiple risk factors, one partner was HIV-negative, one was HIV-positive, and the status of the other was unknown. Two mothers, one in a drug rehabilitation program and one a mother-child detention facility, planned to reside with their partners on their release. None of the other mothers have maintained contact with their partners at the time of diagnosis.

Single with no regular partner. These mothers (6) either described their relationship with the children's fathers as a one-time encounter. They had no intention of maintaining a long-term relationship.

Extended Family

Most of the mothers reported that relationships with extended fancily members became more strained, if not severed altogether. Those that were strained before the diagnosis often worsened following the diagnosis. Some relationships that were considered close became more distant although, generally, those that had been close remained close. A few mothers described instances where the relationship was strengthened. All mothers directly attributed the change in relationships to their HIV infection. Table 20 presents the subcategory, *extended family relationships,* its related concepts, properties and dimensions.

Table 20

Major Category of *Effect on Family*, Subcategory of *Extended Family Relationships*, Its Related Concepts, Properties and Dimensions

MAJOR CATEGORY: EFFECT ON FAMILY

SUBCATEGORY: EXTENDED FAMILY RELATIONSHIP

Related Concepts	Properties	Dimensions
Relationship Enhanced or Maintained	quality (before diagnosis) maternal lifestyle disease knowledge maternal health child health	supportive - - - nonsupportive low risk - - - - - - - - -high risk poor - - - - - - - - - - - - - -good asymptomatic - - - - - - -AIDS asymptomatic - - - - - - -AIDS
Relationship Changed	disease knowledge fear of contagion maternal needs sympathy (for mother)	poor - - - - - - - - - - - - - -good low- - - - - - - - - - - - - - - high low- - - - - - - - - - - - - - - high low- - - - - - - - - - - - - - - high
Relationship Worsened or Terminated	quality (before diagnosis) maternal lifestyle fear of contagion blame toward mother maternal needs	supportive - - - nonsupportive low risk - - - - - - - - -high risk low- - - - - - - - - - - - - - - high low- - - - - - - - - - - - - - - high low- - - - - - - - - - - - - - - high

Mother's immediate family . Mothers most often identified their own mothers and sisters as the primary support persons for both themselves and children. In some families where the woman's mother was elderly, the HIV-positive mothers turned to a sister to assume guardianship for their children, if necessary.

> 28F0.5: That's my mother. I don't think she'd be any different even if I were to get AIDS. I don't think my mother's going to treat me like a freak. I mean, it's common sense, like if I had a child that tells me, "Mom, I've got AIDS," I'm going to love you even though.

> 42F0.5: My mother, she's 72 years old and she's not in too good health herself. My sister. . . she's been a great help and so maybe she'll be able to help me when I get sicker or my baby gets sicker.

Generally, relationships with siblings with whom the mothers were close either remained the same or were strengthened following the diagnosis.

> 45F6.6: My sister told me that 'if you ever get sick, nobody's going to take care of you but me.'
>
> Q: Were you close growing up?
>
> 45F6.6: Yes. We were really close growing up. But with me being HIV-positive and my daughter being HIV-positive, we've gotten really, really close.

A few mothers reported that the close relationship they shared with their siblings no longer existed following disclosure of their diagnosis.

> 42F0.5: My sister, one of my sisters babysits for me, she [has a] positive [attitude]. But my other two sisters and two brothers are very negative. They don't want to come around me; I have nothing to do with them with my child or anything. So that's kind of hard to take when we were all like a close family. We're all like one year apart.
>
> One of my sisters, she won't eat nothing I cook, she won't drink nothing unless it's in a can and all that. Some people are ignorant like that ... like if she uses the toilet behind you or drink out of the same glass or eat on your utensils even though they've been washed, she might get it.

They often included grandmothers of the HIV-positive mothers in their descriptions of their immediate families. In some circumstances, the HIV-positive mother lived with the grandmother.

> 30F8.0: She [grandmother] put us out and wouldn't be bothered with us for about a year.
>
> Q: What made her change her mind?
>
> 30F8.0: Education. I started talking to her about it and having the doctors talk to her about it, my daughter's doctor. Social workers

> told me to call her and talk to her about it. I said, "You call her and talk to her about it." They called and talked to her and they came by and talked to her. With education and books, after a while she started listening. But even now, she'll come back with, 'You know, she might grow out of this.' So I keep saying, "She's not going to grow out of this. She's going to have this the rest of her life."

Other times, because of the grandmothers' perceived inability to understand or preconceived opinion about HIV infection, the HIV-positive mothers did not reveal their seropositive status to their grandmothers.

> 35M3.6: Everybody in my family knows except for my grandmother. She's too old, no way. It's just pointless to tell her. She wouldn't even know what it was. So that's how old she is. She's 89.
>
> 31F1.4: I don't really have much contact with the rest of my family, but I know my grandmother believes this is a punishment against sinners.

More often, however, mothers reported that the family was split. Some members continued their relationships while others became distant or stopped any contact. With two exceptions, all relationships that they described as 'close' prediagnosis remained close postdiagnosis. Relationships that were distant, generally remained distant.

> 35M3.6: My whole family knows. My mom knows, my mom's really supportive. I used to get self-help books, now I get all new articles on HIV. (laughing)
>
> My sister loves me, they love [my son]. My brother and I don't get along at all so he's just not...
>
> Q: Is that because of your HIV infection?
>
> 35M3.6: No, that was just from sibling rivalry from forever. So nothing has changed.
>
> 31F1.4: I have an older sister in Texas who is nurse, so I think she understands and it doesn't bother her. I have another sister here in

> Oakland who just treats me like her little sister, you know, hitting me on the head when she thinks I'm silly.
>
> I'm not close to my dad. We haven't been close for a long time, it's more like being distanced. But I think this has caused even more distance between me and my dad... He says it's not a factor, and that he feels okay about it [HIV], but I think it is a factor for the way he acts. He treats her [daughter] differently than the other grandchildren. It's obvious. He won't touch her, no hugs or kisses. So even though he says it isn't, I think it is.
>
> 37M4.6: My mom was always there for me and this time, with the HIV diagnosis, refused to be there for me (crying). My relationship with her, we used to be really close, has now gone downhill. Especially since I talked about guardianship with my family. My family, I feel kind of distant from because they have made it very clear to me that neither my father or mother want to take on the responsibility of raising my son.

Two mothers also had brothers who were HIV-positive, having contracted the disease through heterosexual contacts. One respondent who had been close with her siblings has no contact with them due to her HIV infection. Her brother, who had also refused contact with her after finding out her diagnosis, was recently diagnosed with HIV.

> 42F0.5: But now we found out that my youngest brother is HIV-positive now. We just found out last month. So my mother's oldest child is positive and my mother's youngest child is positive. So that's hard for her to deal with.
>
> Q: And is he getting the same reaction that you got from your other brother and two sisters?
>
> 42F0.5: Yes. The same.
>
> Q: Since he was heterosexual and not an injection drug user, was he shocked at his diagnosis?
>
> 42FO. 5: Oh, yeah. He did mess around, sexually he messed around so it was a shock to him. But I knew the hard way that you can catch it sexually.

Distant Family

The impact on the mother's relationship with family with whom she has little direct contact, except special occasions, such as weddings, graduations, or Christmas card exchange, was generally dependent on whether they were aware of the HIV diagnosis. Findings from this study did not show any change in distant family relationships because mothers honored requests from her immediate family not to tell. Table 21 presents the subcategory of *distant family relationships,* the related concept of *relationship maintained,* and its properties and dimensions.

Table 21

Major Category of *Effect on Family*, Subcategory of *Distant Family Relationships*, Its Related Concept, Properties, and Dimensions

MAJOR CATEGORY: EFFECT ON FAMILY		
SUBCATEGORY: DISTANT FAMILY RELATIONSHIPS		
Related Concept	Properties	Dimensions
Relationship Maintained	knowledge of diagnosis	known - - - - - - not known

Based on the negative reaction from extended family members, some mothers were unwilling to disclose their infection to distant family members.

> 45M4.0: When some of my family [cousin] found out I was HIV-positive and Rxxx [son] was HIV-positive, they didn't want nothing to do with me and that really hurt me . . . That made me decide not to tell the rest of the family.

However, several HIV-positive mothers were requested by their own family to withhold disclosure to distant family, whether they were local or not.

> 42F0.5: I have an aunt ... and uncles that live in Oakland. But when I told my mother [about the HIV diagnosis], she said, "Don't tell nobody else." Because she didn't want nobody else in the family to know besides the immediate family.

> 37M4.6: I wanted to tell some other relatives but my dad asked me not to, for whatever reason, that there's no need right now. But I was thinking of taking a vacation next year and visiting some relatives while we were still healthy. And I thought that if they had known, that maybe they'd be more understanding (crying) and he asked me not to so I didn't say anything even though I have relatives that give talks on people with AIDS and some of them are counselors. So they are people who would understand and be supportive. So I respected my dad's wishes and I didn't tell them.

Summary

In summary, mothers described the impact on family relationships at three levels: *immediate, extended, and distant* family. In the *immediate family,* only three mother-partner relationships did not result in divorce or permanent separation. Mothers identified infection by her partner or spouse as the primary reason for ending the relationship. One married mother separated to become eligible for financial assistance.

Of *the extended family* members, mothers and siblings of the infected mother were the most likely to be told the diagnosis initially. Generally, across all levels, relationships identified as close by the mothers, remained close. However, a few mothers reported that the close relationship they shared with siblings no longer existed following disclosure of their diagnosis. For those family relationships already strained, they attributed no reconciliation to their HIV infection.

If the mothers were dependent on their grandmothers for assistance, they told the grandmother. Decisions not to inform grandmothers were based on their inability to

comprehend the disease or the grandmothers' preconceived opinions about HIV and AIDS.

Distant family was generally not told of the respondent's diagnosis either because of the infrequency of contact with them or because mothers were specifically requested not to tell.

Blame

From the mothers' descriptions of feelings related to blame; that is, *being blamed or blaming others* emerged the major category of *blame*. The mothers described *being blamed* for the child's HIV infection. They reported *blaming others,* generally their sexual partners who had not revealed either their HIV-positive status or previous lifestyle risk factors. Table 22 provides an overview of the major category of blame, the subcategories *of mothers being blamed by others* and *mothers blaming others,* and related concepts.

Table 22

Major Category of *Blame*, Subcategory of *Mothers Being Blamed*, and Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: BLAME

SUBCATEGORY: MOTHERS BEING BLAMED

Related Concepts	Properties	Dimensions
Being Blamed by Others • physicians • partner • their children (fear of) • other HIV-positive mothers	responsibility (for infection) behaviors	self - - - - - - - - self - - - - - -others & others covert - - - - - - - - - - - - - - - overt
Blaming Themselves	self-responsibility guilt	low - - - - - - - - - - - - - - - - - - high low - - - - - - - - - - - - - - - - - - high

The mothers reported feelings of *being blamed by others* and *blaming themselves* for their child's HIV infection. Mothers who reported feeling *blamed by others* referred to both covert and overt behaviors by the medical care providers, HIV seronegative partners, or family members.

> 45M4.0: (At the time of her child's diagnosis, but before her own diagnosis) 'Well then, you (demonstrates doctor's posture of leaning forward and pointing) gave it to him.' He just said it like that, he wasn't compassionate or nothing.
>
> 36M3.2: He [doctor] told me [child's diagnosis]. I was shocked because I had no connection with that [gay men, injection drugs]. I kind of choked out only sort of sounds out of my mouth and he cut in and just said, 'It was you.'
>
> 28F0.5: He [baby's father] just told me kind of nasty like 'Well, I took the test and it came out negative, so at least I can say that my conscience is clear with my daughter. Can you say the same for you?'
>
> 41F1.1: He [child's father] wants to blame me, but I never blamed it on nobody else. He said maybe it [child's HIV infection] is for all of the wrong you've done.
>
> 37M4.6: Like one [medical assistant] who put me in a room to be examined want to know if I was the foster mother . . . because someone finds out that you have an HIV-positive child, they think that either you were a drug addict or . . . they treat you differently before they even know the situation [of transmission] or find out that I was a victim and not someone who intentionally gave birth while knowing that I was positive.

Only one mother had disclosed the HIV infection to her HIV-positive daughter (8 years old) and the older sibling (10 years old), but did not feel blamed by her children. However, nearly one-fourth of the mothers felt that it was likely that they might have to face being blamed by their own child(ren) in the future.

> 35M3.6: I don't know what it's going to be like when [son] gets a little older and he gets mad at me. I mean, what if he gets to the point where he's mad at me for giving him that [HIV]? I mean, I don't know, I haven't encountered that yet. But I'm very aware that all those things are probably something that's going to be in the near, you know, in the future.

HIV-positive mothers were also blamed by other HIV-positive mothers, although less directly. Within the group of HIV-positive mothers, mothers referred to other mothers by their mode of transmission in derogatory terms.

> 31F1.4: What doesn't help? I'll tell you what doesn't help. It don't help to be a clean infection. If I was a dirty infection [drug related], then I'd get some more help. I know a woman who gets education and childcare respite and support groups because she's with the drug rehab section for HIV women. I only get general assistance with housing.

> 36M7.2: Well, there it is. You got the dirty ones and the clean ones. There's more for the ones who got it dirty and nothing for the ones who couldn't help themselves getting infected.

The concept of ***blaming themselves*** emerged from mothers who expressed feelings of guilt over perinatally infecting their children. Nearly three-fourths of the mothers blamed themselves for having been the vector for their child's HIV infection because they used injection drugs, did not take birth control precautions, or maintained a relationship with an HIV-positive partner.

> 35M3.6 (infection from drug use): And the thing about having a child with HIV is that I feel like I deserve to have it because I did drugs. But my baby never did drugs and he doesn't deserve to have it, it's not his fault ... The guilt is the worst. You can self-destruct.

> 36M3.2 (infection from heterosexual contact): The thing is, it's still hard for me to grasp. Okay if something happens to me, but God forbid if something happened to my son from what I gave him. That's the guilt. There is a lot of guilt.

> 31F1.4: 1 never did drugs, but I got drunk, really stinking drunk and didn't use a condom. So, in a way, I (emphasis) got pregnant.

> 45M4.0: Some days I would wake up and not want to even get out of bed because I was blaming myself because me and my husband had broken up three years ago and then I let him back into my life, into my kids' lives. Then for him to do this to me. I know he knew and then to get me pregnant, too. I was just heartbroken.

One-fourth of the mothers reported they would probably blame themselves if the child's condition worsened or the child died if they did not accept current drug treatment. Mothers cited reasons such as the experimental nature of drug therapies, their uncertain efficacy or long-term outcomes, and the child's current good health state.

> 42F0.5: What's frightening the most is that they want to put my baby on AZT and I don't want my baby to have AZT. And they tell me, 'Well, if you don't put her on AZT then she might die sooner than if she was taking AZT'... So that's the scary situation. Then if something happens to her, then I'll be thinking, '*I should have* gave her the AZT because they *told* me if I don't give it to her, she's going to die.' So that kind of keeps me crying sometimes at night, it just kind of messes with my head a lot. (crying)

> 26M4.3: I cannot see that any of the drugs they use now on kids are really effective for the kids. But they [medical staff] make it seem like its the right thing to do, to try anything you can. But we're probably going to die anyway so if my son seems okay, should I make him sicker with those drugs? But if I don't, could he get better and then not be sick at all? Do you see what goes through my mind?

In addition, several mothers acknowledged that they would probably blame themselves if their child died or became worse if they were to leave the child during respite care.

> 45M4.0: I hate to go anywhere because I'm always worried while I'm gone, will I get the call to come to Children's Hospital? And then I would always wonder, 'If I was there, could I have done

> something?' Especially if he dies. It would always be, 'What if I had been there? I should have been there.' You need to get away, but then it's hard to stay away.

Blaming Others

Most of the eleven mothers whom their partners had infected and who had no other risk behaviors expressed anger about having HIV infection. The mothers shared feelings of anger *directly* toward their partner for infecting them but *ambivalently* toward God for allowing their infection to happen. From the experiences, the concept of *blaming others* emerged, distinguished by qualities of being *directed* or *ambivalent* (Table 23).

Table 23

Major Category of *Blame*, Subcategory of *Mothers Blaming Others*, Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: BLAME

SUBCATEGORY: MOTHERS BLAMING OTHERS

Related Concepts	Properties	Dimensions
Attribution (direct blame)	for responsibility for infection	indirectly - - - - - - - - - - - - directly
	emotion intensity	
	• hate	low - - - - - - - - - - - - - - - - - - high
	• anger	low - - - - - - - - - - - - - - - - - - high
Search for Meaning (ambivalent blame)	emotion	no anger - - - - - - - - - - - - - anger

Ten mothers believed that the infecting partner knew, but did not disclose, his seropositive status directly resulting in the mothers' infection. Feelings of anger and hate were expressed toward these partners to whom the mothers specifically attributed their

infection and, ultimately, infecting their child. These feelings of anger and hate were expressed with an intensity that did not appear to diminish with time.

> 42F.5 (diagnosed 8 months ago): I didn't know that he was an IV drug user before I got with him. See, I didn't know that. Then, when we all got tested, *then* he told me he had it, and so I was very, very mad.
>
> 45M4.0 (diagnosed 4 years ago): I was married and then I separated, but I wasn't messing around, that's why I know my ex-husband had to give it to me... I want to kill him, but I can't find him.
>
> 31F1.4 (diagnosed 7 years ago): I got it [HIV] from trusting him saying there was only me, but I was wrong... I still think about him, the man that gave me this and I hate him, I hate him a lot. I wish there was something I could do to him, like kill him. I would like to kill him I hate him so much.

The related concept of *searching for meaning* emerged from the mothers' descriptions of *blaming others*. Mothers, primarily those without identified risk factors, reported periods of 'feeling sorry for themselves' during which they felt anger toward God for their infection. They reflected the ambivalence of their blame in their anger toward God asking 'Why me?' while denying that God held responsibility or blame for their circumstances.

> Q: You mentioned being angry at God as you tried to figure out 'why you?' In a way, do you think you blamed God for letting this happen to you?
>
> 22F5.0: No, you can't blame God. When I sank into more and more self-pity, I would get mad at God and ask all the time, 'Why me?'
>
> 31F3.4: No, no, I really couldn't blame God. I got mad trying to figure out why this was happening to *me*. For a long time when I was feeling sorry for myself, I would ask God, 'Why would you do this to me, my baby?' I was feeling so sorry for myself I would get mad feeling bad for myself and then I would always be asking.

Summary.

Mothers experienced *blame* through feelings of *being blamed* and *blaming others.* Mothers felt they were *blamed by others* (or likely to be blamed) for their child's infection under certain conditions: at the time of the child's HIV diagnosis, if the father was HIV-negative, or when the HIV-positive child was told. Mothers *blamed themselves* for HIV transmission when they had resumed or maintained a relationship with the infected partner (although they did not know they were at risk); had not taken preventive measures against pregnancy; and had participated in high-risk behaviors that resulted in HIV infection.

The other emergent subcategory, *mothers blaming others,* had related concepts of *attribution* and *search for meaning,* where others were blamed either directly or ambivalently by the mothers for their infection. The women primarily directly blamed HIV-positive partners. However, mothers described a more ambivalent type of blame when they searched for meaning of the experience; inferring some responsibility by God for their infection.

Feeling Helpless

Most mothers expressed *feeling helpless* at several points throughout their experience. Three subcategories related to their experience emerged: helpless to help their HIV-positive child; helpless to help themselves; and/or helpless to help their other children at home. The category will be presented by subcategories and include their related concepts, properties, and dimensions.

Helpless to Help Their HIV-positive Child

Mothers described feeling helpless to help their child when the child suffered an HIV-related illness, the illness became acute, or treatment decisions for clinical trials or drug therapies were recommended. Table 24 presents the subcategory of *helpless to help their HIV-positive child*, its related concepts, properties, and dimensions.

Table 24

Major Category of *Feeling Helpless*, Subcategory: *To Help Their HIV-positive Child*, Related Concepts, Properties, and Dimensions.

MAJOR CATEGORY: FEELING HELPLESS		
SUBCATEGORY: TO HELP THEIR HIV-POSITIVE CHILD		
Related Concepts	Properties	Dimensions
To Provide Emotional Support		
• to provide anticipatory preparation	when	for current illness - - - - - for future illness
• to give hope for improved health or cure	frequency	never - - - - - - - - - - - always
To Provide Physical Support		
• to select best treatment	quality (of knowledge)	low - - - - - - - - - - - - - high
• to alter/ease course of illness	frequency confidence (in nursing skills)	never - - - - - - - - - - - always low - - - - - - - - - - - - - high

Nearly half felt helpless because they were unable to provide their HIV-positive child with anticipatory preparation for their illness course due to the unpredictability and variability of the disease course among individuals. The mothers felt the ability to

provide anticipatory preparation would help the child cope through both the chronic and acute phases of their illness.

> 45F6.6: I can't tell her what will happen or even if she'll get better each time she gets really sick and goes in [to be hospitalized] because I don't know what will happen each time when she gets so sick.
>
> 28F0.5: It's just a scary thing when I found out . . . I would just be breaking into tears because I'm very scared for her. People would look at me like, 'What's wrong with her?' But they don't realize that it will always be a hurt and a fear that would always be inside of me. It would never go away because I don't know what would be the results of it. I just cry because I can't help myself and I can't help my kid.

Moreover, one-fourth felt helpless to offer their child hope during chronic or acute phases of their illness. As with anticipatory preparation, mothers felt offering hope would help their child to cope.

> 43F4.2: So what do I say to explain why she feels bad and how long she will be sick? Nothing. I can't give her hope for something [a cure] that's probably not going to happen. I can't say that maybe the medicine will make her better so she can go to school like her friends. I can't say nothing except that I just don't know.

The conditions under which mothers felt *helpless to help the child physically* were similar to those under which mothers felt *helpless to help their HIV-positive child physically:* to select the best treatment and to alter the course of the illness.

Feeling Helpless to Help Themselves

Nearly two-thirds of mothers felt helpless to help their HIV-positive child or themselves through the physical aspects of their illness. Related concepts, properties, and dimensions of *feeling helpless to help themselves* is presented in Table 25.

Table 25

Major Category of *Feeling Helpless*, Subcategory of *To Help Themselves*, and Related Concepts, Properties, and Dimensions.

MAJOR CATEGORY: FEELING HELPLESS

SUBCATEGORY: TO HELP THEMSELVES

Related Concepts	Properties	Dimensions
To Provide Emotional Support		
• to find peer support	frequency	never - - - - - - - - - - always
• to anticipate acute illness outcomes	frequency	never - - - - - - - - - - always
To Provide Physical Support		
• to select best treatment	quality (of knowledge)	poor - - - - - - - - - excellent
• to alter/ease course of illness	frequency	never- - - - - - - - - - - - -yes

For their children and for themselves, mothers felt helpless when facing treatment decisions, primarily feeling unqualified to select the initial treatment(s) much less challenge ongoing therapies.

> 45M4.0: They got some new drugs out, like 3TC and some combination with maybe AZT and a new drug. Next week they want to try to put that combination together. I want to do anything to prolong his life or to make him healthier. But I just don't know what that is.

In addition, some mothers felt helpless to change the course of the disease for their children or themselves or to even manage the symptoms of the infection.

> 45M4.0: I think it [HIV infection] seems to run faster through a child than an adult. Because [other mothers] were saying how their child was at one [year old], they find out he was HIV-positive; at 3, he had AIDS; and at 6, he's dead. So [my child's] at

> four, so I'm between that time because just two months ago he was diagnosed with full blown AIDS. I'm really scared now.

> 45F6.6: And then there's some days she's up, happy, playing. But most of the time she's just lying around watching TV or in bed. That really hurts me, you know. That makes me cry because there's nothing I can do.

> 35M3.6: Like now, I look at him and I think, 'He's going to die.' And I wonder, '*HOW am I ever going to do this*?' (emphasis) Something happens to him, how am I going to sit in hospitals night after night? I can't do a thing to change things to stop that from happening.

Nearly all mothers felt helpless in finding emotional support specific to the needs of being an HIV-positive mother with an I-HV-positive child due to the non-existence of community-based HIV-positive mother-HIV-positive child support groups.

> 34M4.6: . . . and my need is to find other women who are in my like situation so I can get together with somebody who can relate and share experiences with because telling somebody who doesn't live with their child with the same disease doesn't understand.

Feeling Helpless to Help Their Other Children

Mothers identified the need to provide emotional support to the siblings of the HIV-positive child. They identified two circumstances in which they felt helpless to provide emotional support, such as providing reassurance or anticipatory preparation to the siblings during acute stages of illness and disclosing the diagnosis (Table 26).

Table 26

Major Category of *Feeling Helpless*, Subcategory of *To Help Their Other Children*, Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: FEELING HELPLESS		
SUBCATEGORY: TO HELP THEIR OTHER CHILDREN		
Related Concepts	Properties	Dimensions
To Provide Emotional Support		
• to provide reassurance (that sick child will improve)	frequency	never - - - - - - - - - - always
• to provide anticipatory preparation	frequency	never - - - - - - - - - - always
• to disclose diagnosis	quality (of ability)	poor - - - - - - - - - excellent

Mothers felt helpless to offer the siblings reassurance about a positive outcome for their HIV-positive brother or sister due to the unpredictability of HIV infection.

> 45M4.0: [His 5 year old sister] mothers him along with me. If he don't feel good and he's not going to school, she says. 'I want to stay home with Rxxx today. I might come home and he might not be here.' Then that gets me. I try to be brave in front of her but I can't tell her any different. What can I tell her? I feel helpless because I (emphasis) don't know if he'll be there when they come home from school. (crying)

> 34M4.10: He [sibling] gets tired of him being sick all the time and we always have to depend on how he's feeling before we can go on with our plans sometimes. So when he asks me, 'Mom, when's he going to get better? How come he's sick all the time?' Because he [sibling] knows that it's different for Txx even when they get the same cold . . . And what can I say? I don't know when one cold is just a cold and another cold might mean he goes to the hospital. All I really know right now is that we're okay right now, but that maybe when our luck runs out . . .

Further, mothers felt helpless in deciding when, how, and if to reveal the sick child's infection to the other HIV-negative siblings.

> 45M4.0: I don't know how to tell [siblings] that their brother has something because I can't even tell them what he really has. I just don't know how to tell them that their brother has something that might kill him; that he might die. Or has something that makes people afraid of you, that makes them not want to play with you or they don't want you in their house . . . It's hard.

Summary

In summary, three-fourths of the mothers described feeling helpless to help their HIV-positive child, themselves, or their other children when the child's illness was in an acute phase, when they needed treatment decisions, and when they should make disclosure. Some felt helpless because they faced an unpredictable course of illness; such unpredictability did not allow them to emotionally prepare themself, the infected child, or the siblings for the next illness. They felt helpless to give siblings reassurance that the infected child would get better or not die. They felt helpless not knowing if, or when, the child's bad days would turn into a good day. They felt helpless to decide if, when, and how to tell their other children about the sibling's HIV infection. Mothers felt the only predictable part of the illness was its outcome and they felt helpless to alter or ease that course for their children, much less overcome it.

Hope

Another response from the mothers were feelings related to hope: hopefulness and hopelessness. Nearly half the mothers described feeling hopeless about their dual HIV infection, while a little over half felt hopeful. Six mothers reported having both.

Table 27 presents the major category of *hope*, and its subcategory of *hopefulness*.

Hopefulness

Table 27

Major Category of *Hope*, Subcategory of *Hopefulness*, Its Related Concepts, Properties, and Dimensions.

MAJOR CATEGORY: HOPE		
SUBCATEGORY: HOPEFULNESS		
Related Concepts	Properties	Dimensions
Optimal hope • cure • miracle • outgrow disease	intensity	low - - - - - - - - - - - - high
Realistic hope • ease symptoms • slow disease progression	intensity	low - - - - - - - - - - - - high

The hopefulness that mothers described was directly focused on the child's HIV infection. The nature of their hopefulness emerged as *optimal* or *realistic.* Nearly one-third were hopeful for an optimal outcome: that they would cure the child with or without treatment. Three of those mothers hoped their child would 'grow out of it.'

> 45F6.6: So then her t-cells kept dropping and so I thought I better do something. Cause I was hoping she might grow out of it because some children do.

> 42F0.5: 1 hope that she'll be able to grow out of it. Some kids grow out of it.

> 28F0.5: They told me that . . . my baby would always have the virus which I pray to God he can cure because God can create miracles.

One-half hoped for treatments to slow the virus or decrease opportunistic infections, reflecting what one mother termed being 'realistically hopeful.'

> 45M4.0: I would like to be able to be hopeful together [with other HIV-positive moms with HIV-positive children] that they could find a cure or just slow the process in children.

> 37M4.6: I guess I'm realistically hopeful. I don't think they'll find a cure, but I'm hopeful that they'll find something to get the disease under control so then we can live with it [being infected]. And not have our lives be wasted, just waiting to get AIDS and then die.

Hopelessness

The feelings of hopelessness were generally grounded in their sense of the fatal nature of HIV infection. One-fourth of the mothers attributed this fatalism to their interactions with their therapists or physicians.

> 35M3.6: I used to leave group and be so depressed because he [counselor] would say, 'The bottom line is you're probably going to die from HIV-related disease. Bottom line.' So bottom line I'm just going to die anyway. Why not just shoot myself now?

> 25M1.8: His [physician] approach is like, live the best you can, clean, etc. but you're probably going to die anyway. So I leave there going like, why bother with my child? Why bother? That's how I feel.

> 45M4.0: Going by what the doctors say about him [5 year old son] being sick all the time, it don't give you a lot of hope to think he might get to be a teenager someday. The doctor said he could get full blown AIDS any time now.

> 28F0.5: . . . I have a doctor who didn't give me no hope at all. [He said] 'Eventually, you'll just get AIDS.' Another [doctor] said, 'We know of people who have lived with the virus for a long time and never got it . . . ' So, some doctors, they don't give you no hope at all. They just tell you like a kick in the ass. I mean you're scared of it as it is and then they tell you eventually you'll get AIDS. What kind of hope is there in that?

One mother felt hopeless as she experienced the death of her support group

members. At the time she stopped attending her group, she was the lone survivor of the original ten members.

> 30F8.0: Two years ago I was severely depressed . . . crying most of the time and felt a great sense of hopelessness. I had about ten different friends, we were always at the women's support group run by the AIDS Foundation and, right now, I'm the only one still living from that group.
>
> I didn't start attending til '90. Between '90 and '94, everyone passed away except for me. Some would pass [die] or one of their kids would pass. I couldn't deal with it anymore and still have hope.

Table 28

Major Category of *Hope*, Subcategory of *Hopelessness*, Related Concepts, Properties, and Dimensions

MAJOR CATEGORY: HOPE

SUBCATEGORY: HOPELESSNESS

Related Concepts	Properties	Dimensions
Sense of Fatalism	intensity	low - - - - - - - - - - - - - - -high
Death of Friends (Support Group)	frequency	never- - - - - - - - - - - - - often

Summary

In summary, all mothers expressed either hopelessness or hopefulness; six described both emotions. Hopelessness occurred in circumstances where their care providers' projected a fatalistic attitude of the disease outcome. Watching friends or group members become ill or hearing reports of deaths contributed to feelings of hopelessness.

However, mothers were hopeful for an *optimal* outcome for their child's illness: being cured or outgrowing the disease. Other mothers held *realistic hope* for the development of treatments to slow disease progression or permit better control of opportunistic infections.

Disclosure

Mothers were continually faced with the decision of whether to disclose their own or their children's HIV infection to others and even to their own children. They described others as anyone other than their partner or spouse, child or child's siblings, and their own mother. From the data emerged the major category of disclosure with a subcategory of *deciding to tell* with concepts related to the ability of the person to understand the physiologic and/or psychosocial implications of HIV infection, the mother's perceived risks to herself or her children, previous reactions from others, the desire to maintain her self-identity, external input (from family or friends), and whether there was a need for someone else to know. Table 29 presents the concepts, their properties, and dimensions.

Table 29
Major Category: *Disclosure*, Subcategory of *Deciding to Tell*, Related Concepts, Properties and Dimensions

MAJOR CATEGORY: DISCLOSURE

SUBCATEGORY: DECIDING TO TELL

Related Concepts	Properties	Dimensions
Timing of Disclosure	cognitive development	concrete - - - abstract
Perceived Risks (to child, self)	intensity (of perception)	low - - - - - - - - high
Actual/Previous Reactions from Others	quality	negative - - - positive
Preservation of Self-Identity	change (in role)	sick role - - well role
External Input	family relationship to mother	distant - - - - - - -near
Need to Know	extent (of need):	
	• child's health needs	low - - - - - - - - high
	• risk of contagion	low - - - - - - - - high

Timing of Disclosure

Mothers based their decision to tell their HIV-positive child and/or the siblings on what they perceived the child would be able to understand about both the physiological and psychosocial implications of HIV infection. One mother disclosed the dual infection to her 8-year old HIV-positive daughter and the 10-year old sibling. No other children knew of their HIV status because mothers felt they were too young. Nearly all the mothers believed they would tell their child and/or their siblings when they reached a certain 'level of understanding,' which they associated with the tenth birthday.

Perceived Risks

All mothers discussed their dilemma of whether to tell anyone else. More than four-fifths of the mothers agreed that exposure (of their infection) was the most important risk they faced in telling others. The risk had two aspects: that others would find out and that their HIV-positive child and/or the siblings would find out as well. When they perceived the risks of rejection, isolation, or physical harm to be high, they did not disclose. When they perceived that exposure of the infection might result in their HIV-positive child and/or their other children (who did not know diagnosis) finding out, they did not disclose as well.

> 42F0.5: Nobody. I don't tell nobody. Because the stigma and things you've heard about people, people breaking into people's houses, burning their house down. You know, people hate people with AIDS and is scared of people with AIDS.
>
> 31F1.4: Well, I haven't told anyone [except father and siblings] I have it. I don't really want to go public with it, like with my father's friends or our family friends, outside the family . . . I am afraid of the stigma against my family and my child. Like my dad . . . I wouldn't want him to experience

> anything like having someone throw it at him that 'Hey, isn't your daughter that one that's got AIDS?' Especially with him since he's got a job working with the public.
>
> 45M4.0: So when I bring my kids to Sunday School, people pick them up and hold them, you know. And I wonder if they did know, even though they're supposed to be church or religious people, would they still pick them up and hold them, *if they knew?* Even though people say they're all religious and believe in the Lord and all that and not supposed to judge anybody or anything, but it just might be for AIDS, like 'Oh, no. I don't want to touch him,' and not know anything about AIDS or HIV.
>
> 45M4.0: It's hard because the school and day care are connected and they're worried about him because he's always sick and always has ear infections, thrush, pneumonia. If the school knew, then it could get blown out of proportion and then they might not want my kid to go to that school. Then everybody might know [the child's diagnosis] before my kids even know.
>
> 45F6.6: I haven't told the people at the school that she's positive because I don't know how they would react to that.
>
> It's like, just so much stuff you see, on TV like when this boy was really fighting cause he wanted to go to school and the school didn't want him coming to school. And so I feel like if I tell them, they might not want her to come into that school. Some parents are ignorant and don't want their kids to play with other kids who are HIV-positive.
>
> 37M4.6: Even people who are educated and work in the health care field all don't have the same positive feelings on [AIDS]. I just worry about the attitudes that people will have . . . I worry about being ridiculed and mistreated, the most that I worry about is the attitudes of the parents of the patients . . . I don't think they would let me work with children if they knew . . . I don't think that if the word got out that I would be able to continue working there.

Actual/Previous Reactions from Others

Besides what the mothers feared would happen, their experience with disclosure also influenced their decision to disclose. None of the mothers reported supportive reactions from others that encouraged them to disclose their infection. However, more

than half reported experiences that resulted in negative reactions, further restricting the circumstances in which they would disclose their own or their child's infection.

> 45F6.6: My sister's ex-husband tried to use the fact that I was unsafe and he didn't want, when he was getting divorced, that he didn't want her to have the kids. Because in the courtroom they brought up the fact that I have HIV. [He said] 'You know your Aunt Xxx is sick.'
>
> 31F1.4: Well, for example, I get meals from the Open Hand [food delivery to HIV clients] people several times a week. The delivery people have always been nice, taking time to talk to me sometimes, and not being like they were afraid to be near me or touch me. But just a few days ago, a driver came . . . when she tried to hand me the meals, she acted like this (demonstrates motion of her arm fully extended, holding something between her thumb and index finger). That shows that you need to be careful who you tell and not be too open with it with other people.
>
> 30F8.0: Not too many friends and none of my neighbors know. I know people to this day talking, 'Oooooh, I heard so-and-so got the virus. Oooooh, better stay away from them.' You know, people live with the virus. You can talk, play, hang around them, eat, socialize with people and have no problems. 'Oooooh, but that virus, that's something else. You don't want to mess around with it.' You hear people talk like that.
>
> 45M4.0: My cousin, Wxxx, she had just had a baby and I asked her could I hold her baby and she didn't want me to. So that made me decide not to tell the rest of the family. Some people don't know you can't catch it just by touching. Then, too, when some of my family found out I was HIV-positive and [my son] was HIV-positive, they didn't want nothing to do with me and that really hurt me. That really hurt me. They didn't want to hold him or nothing, because they were scared. They were afraid of him.
>
> 28F0.5: Well, like I thought it was a good thing to tell people, but it's not when you're in a place like this [mother-child detention facility]. I got in an argument with one of the girls and she yelled at me, 'You're infecting us, bitch. You and your baby aren't even supposed to be here.'
>
> 25M1.8: . . . I got hurt behind knowing a lot because one of the other girls would say, and it always stayed with me, 'Don't let her hold your baby. Don't let her kiss your baby because she's got AIDS.' (crying) . . . A lot of people don't want to test and I don't blame them now, because they're afraid people will treat them like freaks . . . . I've been made fun of a lot

> and I've been hurt just knowing and it'll always be there . . . . I will never forget how they make me feel like I was a freak. I will never forget it.

Preservation of Self-Identity

Some mothers, after telling their own mother and siblings, did not intend to tell anyone else other than their HIV care providers. By maintaining their 'well' role identity, mothers did not have to risk rejection or isolation from friends or co-workers.

> 37M4.6: Some things you can't be sure about [disclosure]. How could anyone know what anyone else is really feeling until it happens to them? Right now I need to belong here [at work], because someday I might not have anywhere.

> 28F0.5: I've noticed people who have told people who thought that they were close [friends], that knew each other since they were kids . . . and [they] told them and all of a sudden they just freaked out and left.

They expressed their desire to maintain their 'well' role identity (co-worker, friend) and not become the 'person dying of AIDS.' In the few instances where others did not reject the mother, her disease became the focus of any interaction. She felt people became too concerned at any deviation from her normal self.

> 30F8.0: [My sister] like goes up to me and whispers, 'You okay? You okay? You're not going to die are you?' And I just go, 'I got a cold. Leave me alone.' She's the guy who shouldn't been told. [laughs] . . . She's afraid for me.

> 41F1.1: I know they all love me, so I'm not saying this like a burden or nothing. But as long as I'm feeling good and not feeling like I got the virus, they don't need to know really what's wrong . . . they'd be *too* worried about me. I don't need to be taken care until *I need* to be taken care of.

Maintaining their 'well' role identity also allowed mothers to distance themselves from their illness, which one mother felt helped her cope with her infection.

> Q: So what helps you get through this [experience]?

> 31F1.4: I'm the person I was before [being infected] because I pretend I don't have it. I ignore it and just put is out of my mind and as long as I'm feeling okay, I don't have to think about it. *I don't have it* [emphasis] . . . I just think, 'I don't really have it.'

Concealing their illness required the mothers to maintain secrecy about their disease. The consequences of doing so resulted in living a 'double life' and limiting their resources.

> 42F0.5: You feel like you're under a microscope when you go out, because of the secret life you've been living. Do they know or don't they know? But then, you know, to tell somebody would be damaging to me *and* my baby. Somebody might want to try to hurt us. That's how I feel about it.

> 30F8.0: . . . that's the one thing with this [not telling diagnosis], you know, you got a double life. Because you can't really tell anybody. You *want* (emphasis) to tell everyone, the whole world, but there's still a lot of stereotypes, a lot of ignorance, and lot of prejudice towards it.
>
> There are those I would like to tell and trust and to know that it's not a secret. With their confidence, we could talk freely and openly and talk about whatever's on my mind. Instead, I have to sit there and pick and choose my words, saying cover-up words that don't really say what I mean. I hate having to lead a double life sometimes. So instead of leading a double life, I leave a lot of folks alone . . . I don't have no more patience trying to pick and choose my words and lie about what's going on.

> 31F1.4: Well, when I need some help, because I'm feeling bad or hopeless or feeling sorry for myself or for other things even, I can't tell people why I need help. Besides my family, nobody knows except [friends] in Florida . . . So when I need help, I feel like I can't get the real help I need. Some people think I have cancer, my dad's mother told everyone that. So people don't give me the help I need, because they don't really understand *what I* need.

External Input

One-fourth of the mothers were requested by their own parent, generally their mothers, not to disclose to extended or distant family members, even those with whom

they had regular contact. All mothers whom their family requested not to tell either friends or relatives did not disclose their infection.

> 42F0.5: I have an aunt that lives in Oakland and uncles that live in Oakland [same city as mother]. But when I told my mother, she said, 'Don't tell nobody else.' Because she don't want nobody else in the family to know besides [her] immediate family. So it is very hush-hush.

> 37M4.6: I wanted to tell some other relatives, but my dad asked me not to, for whatever reason, that there's no need to . . . So I respected my dad's wishes and I didn't tell them.

Need to Know

In deciding to tell, mothers considered the other party's *need to know.* Mothers identified others primarily as care providers, either health care or school, or future sexual partners. The extent of the *need to know* focused on the risk of transmission to others and the medical needs of the child or themselves.

Risk of transmission to others. Nearly all the mothers expressed extreme concern about transmission risk to other children in the day care or school settings. Four mothers had school age children. Three attended public schools and one did not due to the mother's indecision about disclosure. Of those three, two had informed the school of their HIV-positive status. Fourteen mothers had their preschool age children in day care or preschool settings; eight disclosed their HIV-positive status and six did not. Two mothers were not sending their children to day care or school.

> 36M7.2 (disclosed to day care): I didn't feel comfortable sending him to a day care that didn't practice universal precautions. I was not only for his protection, but any of the other kids' protection.

> 45F6.6: I'm going to try to talk to Dr. Ssss, therapist, again. I already talked to her and she said don't tell them [school]. But I'm scared if she

> gets hurt or she gets sick. And then, she has to take her AZT to school with her, too.
>
> My mom thinks she should go [to school]. But then I told her she has to take medication or she gets sick, she gets sick real easy. If she eats something that don't agree with her, she gets diarrhea or throws up. It's hard.

For mothers, concern about potential transmission to others extended to future sexual partners as well.

> 28F0.5: To me, you shouldn't tell nobody. You *should*, but you *shouldn't*. If I were to bump into somebody in the future, like I liked a guy and the guy like me, I'll tell him, but not right away . . . but I have to tell him I have it.

Health care needs of mother or child. The other aspect of the *need to know* concerned the extent to which disclosure affected receiving proper medical treatment. Health care providers needed to know to provide appropriate treatment.

> 35M3.6: Not only am I woman with HIV, I am a mother of a child with HIV and so that is my priority in disclosing. When I tell, it has to be with the interest of my child who has HIV so that he can get the care that he needs and get the appropriate care. Telling half the story or giving out one piece of information is risky for not getting the right care for my child. That's what has to come first.

Although all mothers had primary care physicians, two believed there was no need to disclose to non-primary care providers, such as the emergency room or urgent care clinic personnel.

> 36M3.2 (seen in urgent care clinic): . . . so then [after disclosed HIV status] the doctor came in, then the R.N. came in, and they all asked these personalized questions like how I got it and did I have sex . . . like that's none of their business, so now I only give them [non-primary care providers] a little bit [of information].

> 42F0. 5 (did not disclose in emergency room): After she was born she had

> a sore throat and cold and ear infection all at once . . . so even though I had taken her home. . . the ear infection kept recurring and recurring. So I took her to the E.R. and then they took blood tests and then they knew we were positive, because I didn't tell them at first.

Mothers informed the day care or school when their child required medication during school hours. Eight children required medication administration during their hours at childcare or school and all had notified their school. Of the ten who did not require medication during school hours, six did not disclose to the child's day care or school.

Summary

In summary, six major concepts related to *their decision to tell others* about their HIV diagnosis emerged from the mothers' stories. When they perceived that the risks of having their illness exposed were high or their experiences were negative, the mothers were reluctant to tell others. If they wanted to maintain their previous 'well role' identity, such as a mother, a sister, a co-worker, mothers maintained secrecy about their diagnosis. Moreover, when family members specifically asked them not to tell, they did not tell. However, if there was a need for others to know, either due to possible transmission risk or to obtain medical care, mothers disclosed their seropositive status. All mothers felt that they should tell their children and siblings of the diagnosis when they were capable of understanding, generally around ten years of age.

Coping

The women identified strategies to manage their illness and emotional distress. This section presents the mothers' efforts to manage their illness by maintaining their health, managing/prioritizing their needs, and performing skills. Strategies to decrease

their emotional distress included seeking other HIV-positive mother and HIV-positive child support groups, maintaining hope, and seeking meaning to their illness. These strategies are described below in Table 30.

Table 30

Managing Their HIV Illness: Problem-Focused and Emotion-Focused Strategies

Coping	Strategy & Objectives
Problem-focused: Managing the illness	Maintaining health • follow treatment regimens • health promotion • preserve pre-illness identity
	Managing/prioritizing needs • live one-day-at-a-time • time conservation
	Performing skills • decrease anxiety
Emotion-focused: Controlling emotional distress	Seeking support • obtain reassurance, empathy • share information
	Maintaining hope • decrease feelings of helplessness or despair • long-term goals for child
	Seeking meaning • 'Why me?'

Shared Strategies	Seeking information • increase knowledge to support decision-making • develop support resources • decrease uncertainty/anxiety Maintaining normalcy • preserve 'well role' identity • distancing/suppression Suppression of illness • avoid emotional distress

Problem-Focused Coping: Managing the Illness

Maintaining health. This was the primary strategy hopeful for a cure, a miracle, or advances in treatments. They believed maintaining an optimal level of health for themselves and their child could prolong their survival so they could benefit from medical advances in HIV treatments.

> 35M3.6: I pray, but that's not what's keeping me going. What's keeping me going is medically they are going to come up with something and I'm going to be here for it. And even if they don't, I'm going to take care of myself the best I can, and I'm going to take care of my son the best I can until it's my time.
>
> I'm just hoping that they're going to come up with something and that I can keep him healthy until then . . . . If I just keep him in really good medical care, the same with myself . . . . if we do that, we have a good chance of being long term survivors.
>
> 30F8.0: As long as we take our medications and take care of ourselves, we could do very good with this [HIV]. It's when we don't take care of ourselves that we take a chance and not live.

Managing/prioritizing needs. Nearly all the mothers focused on *addressing needs on a day-to-day basis.* They attempted to manage financial and physiologic needs by

focusing on short-term or immediate issues. They applied time conserving tactics such as budgeting time to include traditional treatments, streamlining household procedures, and consolidating activities.

> 45F6.6: I look at it day by day. There's not enough money. It's not having enough money to get some of the things that my daughter wants because we're on a very limited income. So I have to take it a day at a time.
>
> 35M3.6: I do think that you just *deal* with it . . . don't get too frightened, just take what's in front of you.
>
> 308.0: Basically, I do the day to day . . . . [I] make sure medication management is taken care of for myself and the child on a day-to-day basis. Make sure everybody get enough rest from a day to day basis, get enough to eat. If there's problems, you take them one day, you can't just let them stretch too far along because we know that there might be another tomorrow or we don't know that there might be another tomorrow.
>
> 36M7.2: I have all those fears [of failing health] and they're all real. But until that, I mean I'm just living one day at a time like . . . I don't worry about that kind of stuff [what may happen], but I don't block it out of my mind. I know it's there and I know it's a possibility, but I'm not going to worry about it today.

Performing skills. Mothers felt they needed to learn certain skills so they could provide the best care for their child. They learned most skills as they needed them; that is, there was no opportunity to practice the skill beforehand. Learning the skills was effort - intensive causing anxiety and stress, but once learned, mothers reported their performance as very good.

Emotion-Focused Coping: Managing Emotional Distress

Seeking support. Mothers sought support from family, friends, and AIDS agencies to obtain respite from the emotional stressors of being the sole care provider. They sought

support from other HIV-positive mothers with HIV-positive children seeking reassurance, empathy or comfort, and sharing information.

> 42F0.5: [My] friend, me and her, we're close friends and we both have daughters, you know, with the virus, so we support each other. And another lady has a daughter with the virus and we all just kind of clicked together to support each other. We talk to each other and see each other about twice a week in group groups. So that's what's been holding me together right now.

> 45M4.0: What helps? My family. I could talk to my mother or my other two sisters.

> 28F0.5: I like the (support groups] in San Francisco and Berkeley . . . . When you go in there, there's nothing but people who are HIV-positive or people who have AIDS. . . . They cook meals and also help me like they donate clothes. I like it because they shop and give you groceries.

> 31F1.4: I go to the Center in Berkeley and the support groups, they help. To have somewhere to go and be with other people like me.

> 30F8.0: [It helps] having somebody like Bridges for Kids . . . that helps you with your kids, you know, they take them away and leave the house, they give you time away from the kids.

Although only eleven mothers were active participants in an organized religious group, nearly all the mothers found comfort and hope in praying. Some who had been ambivalent before their diagnosis reported having a greater spiritual faith following their diagnosis.

> 42F0.5: *Now* I do [pray a lot]. (laughs) Well, I've always been religious. I think everybody is. And you go to church, but when something like this happens to you, then you really start trusting in the Lord and start praying.

> 31F1.4: What really helps me is faith in God. I wasn't ever really serious about it [religion], but after I found out while I was in Texas, the minister's wife took me to a revival meeting. I felt the Lord enter me and I like became awakened. Ever since, I have become convinced that praying helps me get through the depression and the self-pity.

> 45M4.0: If I didn't pray a lot and my family wasn't there for me, I wouldn't be here today. It is just too much . . . . Because I don't think if I wasn't in church I would be able to handle it like I'm handling it now because my pastor is a great source of comfort to me. That helps me a lot.

Maintaining hope. Whether mothers expressed their hope for a cure or for better treatments, simply having hope lessened their emotional distress, their feelings of despair. Mothers reported that keeping a positive attitude helped them maintain their hope.

> 35M3.6: You know, I mostly live optimistic . . . . so I kind of mostly focus my energy on that kind of stuff And I don't try to be depressed like What if he gets this, like pneumonia, what if he gets that, all that kind of stuff. And I'm not in denial that that might happen, that very well might happen. But it's not happening today.

> 30F8.0: . . . she [HIV-positive child] does know that as long as she keeps good, positive thinking about herself and about who she is and what she should do for herself, she'll live. I watched people as they got negative attitudes about living and about the virus . . . that's when they started dying. . . . You know, the ones that are really kicking in there and try to live and stretch it out and do what they got to do to live, they've been around ten or fifteen years.

Mothers also felt that while, of necessity, they needed to focus on day-to-day management of their illness. However, they felt strongly that their child needed to have long term goals, whether for a special event or for regular life activities.

> 45F6.6: I'm trying to save up some money to go to Disneyland. That's her dream, to go to Disneyland. So that's what I'm really trying to save some money so she can have a dream.

> 36M7.2: Basically I do the day-to-day. But for my children, I do the day to day, but try to look forward to a better tomorrow. Like finishing school.

> 30F8.0: We live basically day-to-day but we do have long term goals as far as the *kids* are concerned. We want them to have assurance that if they want to get married, let them get married. All that kind of stuff. You know goals are very good for them.

Further, mothers felt that giving back to the community contributed to their positive attitude and supported their feelings of hope.

> 35M3.6: I give back [to the community], like I do volunteer work, too. Even though [disclosing to groups] is uncomfortable, it might help someone else.

> 31F1.4: You know what really helps, too? Public speaking. I started several months ago. I participate in the WEDGE Program in San Francisco. I work with teenagers and tell them about myself and what happened to me. I don't do drugs, never have. It was just sexual contact.

Seeking meaning. Eight mothers (no identifiable risk factors) turned to God in their search for meaning for their own or their child's HIV infection. Five of those mothers believed their purpose was to serve as messengers about AIDS. Three could not attribute any meaning to their infection.

> 31F1.4: Like I used to ask all the time, 'Why me?' I think there's a purpose to this. I think my purpose is to be an example to young people, teenagers, to get the message to save more people. You know, my message is that I'm really one of them. I never did drugs, but I . . . didn't use a condom.

> 30F8.0: I love church. I love God. But for a long time I looked at God and said, 'Why you let me into a situation like this? Why you let my family go like this? Why? My mom, my daughter, me, my husband, everybody. Why?'

Most of the mothers with histories of injection drug use and/or prostitution attributed their infection to these behaviors. One mother with a history of high-risk behaviors felt the purpose of her infection was a warning from God.

> 28F0.5: I know in my heart this is God telling me to stop with the drugs or you'll get AIDS. That's the message I got from God, you know.

Shared Strategies for Problem-Focused and Emotion-Focused Coping

Seeking disease information. As presented in the previous discussion, mothers

sought to increase their knowledge base in order to select or deny treatment for themself or their child. However, seeking information also served to decrease mothers' feelings of anxiety related to the uncertainty of the trajectory of HIV infection and/or AIDS.

> 43F4.2: And I was frightened. And I think the more I know about it, the less frightened I am about having it. You know?

> 35F3.11: It was very difficult to watch that [child's deteriorating health]. I learned all I could from wherever I could and so I understood about her encephalopathy, that she had PCP four times, and that when she was diagnosed with CMV, I knew it was time to decide what to do . . . Learning all I could made me realize that she was dying and so maybe I was more accepting that she is dying, but it'll still break my heart when she leaves this world.

The amount and type of information mothers wanted varied. However, mothers focused on obtaining information about current and upcoming clinical trials, treatments, and clinical markers. Mothers used their increased knowledge to participate in treatment decisions and to increase their support resources. Their primary sources of information were HIV/AIDS centers, educational programs, and their primary-care health care providers.

> 43F4.2: . . . I knew that I had to deal with having a life-threatening disease, I had to find out about it . . . The more I know, then I feel like I know I can say 'yes, we'll do this' or 'no, I don't want to do that.'

<u>Maintaining normalcy</u>. As previously presented, some mothers preferred to consciously conceal their illness which allowed them to maintain their 'well' role identity. Doing so allow them to avoid, even temporarily, the emotional distress of having a life-threatening illness by distancing themselves from the illness by suppressing their HIV infection.

> 31F1.4: I pretend I don't have it [HIV]. I ignore it and just put it out of my mind and as long as I'm feeling okay, I don't have to think about it. *I don't have it.*

> 41F1.1: And I don't dwell on it [having HIV]. It's not happening to me. I pretend it's not me with it.

Suppressing the illness. Suppression, the conscious decision to conceal their illness, was also a means for the mothers to avoid emotional distress. If the mothers and their child remained in good health, requiring almost no treatment, suppression provided temporary postponement of dealing with their emotional distress.

Summary

In summary, mothers identified strategies to cope with the physical and emotional aspects of their HIV illness. Strategies that emerged from the data were presented as problem-focused coping, emotion-focused coping, or as shared strategies for both problem-focused and emotion-focused coping.

Problem-focused strategies managed the physical aspects of the illness and included: maintaining health, managing needs, and performing skills. Emotion-focused strategies managed the emotional distress of the illness and included: seeking support, maintaining hope, and seeking meaning for the illness. Strategies to manage either the physical or emotional aspects of the illness included: seeking information, maintaining normalcy, and suppressing the illness.

CHAPTER FIVE

DISCUSSION OF FINDINGS

The research on chronic illness has been based on a disease-by-disease or categorical approach. This approach organizes knowledge by organ systems, emphasizing the unique characteristics of individual diseases within each system (Pless & Perrin, 1986). The categorical approach has worked well as the organizational framework for the intensive medical specialization needed to develop and implement specialized diagnostic and treatment modalities.

However, it has been recognized that chronic illnesses may also be viewed from a noncategorical approach, that is, chronic illnesses have commonalities in their impact on individuals and their families despite their individual disease processes. The case for commonality across chronic illnesses was derived from studies of individual disorders and examination of literature that revealed the existence of common patterns across most conditions (Pless & Pinkerton, 1975). In his study of chronic illness, Strauss (1975) identified prominent features of chronic illness that affected every aspect of the individual's physical, emotional, social, and financial experience. Thus, the noncategorical approach proposes that common issues exist regarding impact and adjustment of disease on families as well (Sabbeth, 1984).

Human immunodeficiency virus infection affects every aspect of *any* HIV-infected individual's life. Powerful emotional reactions may emerge for the infected individual as well as family and friends (Lippmann, James, & Frierson, 1993). Behaviors associated with greater health risks may manage the intense stressors faced (Thompson, Nanni, &

Levine, 1996). Demographic variables such as ethnicity and socioeconomic status become factors in treatment and outcome (Hogg, et al, 1994). Uncertainty and stigmatization permeate the experience (Laryea & Gien, 1993; Weitz, 1989).

What, then, is the experience when the chronic illness is HIV infection and the infected individual is a mother whose child is also HIV infected? This chapter summarizes the research findings investigating that question and addresses their relationship to the current body of literature concerning current HIV/AIDS research. Implications for nursing and directions for future research will conclude the chapter.

Significance of Study Findings

The following section will discuss the major categories that emerged from the HIV-positive mothers' stories of their experience. Each section will summarize the findings by categories: (a) uncertainty, (b) stigmatization, (c) finding out the diagnosis, (d) blame, (e) feeling helpless, (f) hope, (g) disclosure, and (h) coping. Discussion will include their significance to HIV-positive women in general and to the HIV-positive mother-child family in particular.

Uncertainty

Studies investigating the phenomenon of uncertainty cannot help but emphasize that life itself is uncertain. As such, it has principles of universality (it is a condition of human existence) and multidimensionality (it varies in degree of magnitude, intensity, and saliency) within the construction of an assumptive world (having order and stability, continuity and coherence) (Cohen, 1993). Accordingly, although the realities of living include the potential for unpredictable, devastating events, life is lived as if that reality

were stable and orderly, thereby reducing the amount of perceived uncertainty. Consequently, the unexpected is never expected. The diagnosis of HIV infection is one such event in which the individual experiences an abrupt break in their present world, confronted by the unexpected.

Uncertainty has been identified as a major experience of the individual with HIV/AIDS (Gaskins & Brown, 1992; Katz, 1996; Weitz, 1989) as well as their caregivers (Brown & Powell-Cope, 1991). Although little research has specifically targeted HIV-positive mothers, findings from this study support the reported experiences of uncertainty of parents of a child with a life-threatening disease and as individuals with HIV-infection. Further, this study adds insight to selected concepts specific to the experience of the HIV-positive mother-child dyad.

Course of Illness

The experience of uncertainty related to disease course and outcome has been reported by HIV-positive individuals and their caregivers (Brown & Powell-Cope, 1991; Weitz, 1989). Similar experiences were reported by the mothers in this study as well. All mothers, like the caregivers (Brown & Powell-Cope), expressed concern about the unpredictability of their child's HIV infection. They could not foretell the timing nor the ultimate severity of recurrent infections. Consequently, mothers were uncertain when to provide anticipatory preparation or when to reassure the infected child or siblings that the infected child would get better.

Mother's Management of Child's Illness

All mothers in the current study experienced at least one or more of the four

components of uncertainty in illness proposed by Mishel et al. (1984). Nearly all expressed uncertainty about being unable to identify the state of their child's disease; that is, to say how their child actually was. This supports the findings of Cohen and Martinson (1989) whose parent respondents felt that the consequence of their child's life-threatening diagnosis, cancer, increased their feelings of vulnerability in their ability to appraise their child's health accurately and seek appropriate levels of care. Although fourteen mothers in this study reported their child's health as good to excellent, descriptions of their health ranged from having no symptoms to chronic diarrhea and ear infections to a drop in T-cells from 1500 to <300 or a viral load >100,000. Another one-fourth felt uncertain in selecting or challenging courses of treatment due to their lack of HIV physiology and pharmacology knowledge.

Disclosure to Child.

The uncertainty related to disclosure reflected the findings of other HIV-positive mother-child studies. Like the HIV-positive mothers in Cohen et al. (1995), the eighteen mothers in the current study, whose HIV-positive children were unaware of their diagnosis, were uncertain about when to disclose. Mothers in this study also expressed the same concerns identified by Andrews et al. (1993) related to their uncertainty about the reactions generated by disclosure; that is, reaction from others toward the child and reactions from the child toward the mother. Fears of rejection or physical harm toward the child and fear of anger or blame toward the mother were identified. The mothers focused their concerns on the potential impact on their child, not themselves.

Child's Having a Sense of the Future

This concept could not be clearly identified in the HIV-positive mother-child dyad research literature available at this time. Data from this study's findings were not sufficient to substantiate this experience as a concept. Some elements may be related to having a goal-oriented future presented in the literature addressing hope (Hall, 1994), but such distinction cannot be made from the current data. Consequently, this finding can only be presented as an area for future research at this time.

Living After Dying

Another concept that emerged from this study, *living after dying*, in which the uncertainties related to the mother predeceasing the child as well as the child predeceasing the mother were identified. This concept has not been explored substantively in HIV-positive mother-child research, although maternal concerns of predeceasing their child, such as custody and care of all surviving children, and of children predeceasing their mother, such as depression and loss of reason for living, have been discussed in the literature (Chung & Magraw, 1992; Cohen et al., 1995; Levine, 1995; Septimus, 1989).

Findings from this study supported the concept identified by Weitz (1989) where respondents felt a major area of uncertainty surrounded their ability to live and die with dignity. While none of the HIV-positive mothers expressed concern for themselves, most expressed concerns about their child dying and their ability to provide comfort and dignity for the child during those final moments.

Strategies for Managing Uncertainty

The HIV-positive mothers in the current study described strategies to manage

uncertainty similar to those used by parents of children with cancer (Cohen, 1993). The mothers in this study managed time by living one day at a time, with long term goals set at two to three months. The most stressful social interaction involved, disclosure, was controlled by withholding, limiting, or disguising their child's diagnosis. The mothers also actively participated in seeking to increase knowledge. However, they managed unwanted information (such as estimations given of time from AIDS symptoms to death) by filtering the information; that is, either discarding the information, discounting the credibility of the source, or seeking exceptions to the unwanted information.

However, the HIV-positive mothers varied from mothers of children with cancer in managing the illness. Mothers in the Cohen (1993) study focused on controlling their child's physical environment to decrease the danger (of injury or infection) to their children. Mothers with HIV-positive children focused on controlling the environment to decrease the danger (of contagion) to others, particularly other children. Unlike the mothers of children with cancer, mothers of HIV-positive children do not have reliable disease indicators on which to predict HIV-related illness outcomes and so it was difficult for them to assess the magnitude of danger to their child.

Almost all mothers in the current study acknowledged the concern that they would predecease their child and the quality of life for their HIV-positive child (even their other children) still living would be uncertain despite their best efforts at planning. Some mothers in the current study had arranged legal custody for their children with extended family members, usually mothers or sisters. Others, who had no such assurance from their families, attempted to strengthen family relationships, increase networks with other HIV-

positive mothers, or arrange legal custody to friends. Two mothers said they could not bear to think about the possibility that they would die before their children and had not arranged for their care.

It is clear that HIV-infected mothers with an infected child share some noncategorical experiences experienced by other individuals with a life-threatening chronic illness as well as sharing some experiences attributed to other individuals with HIV infection. However, the dual nature of the mother-child infection adds yet another dimension to the experience of uncertainty of illness in HIV infection.

Stigmatization

The discussion by Goffman (1963) of his concept of 'spoiled identities,' identifies stigma as the incongruence between an ideal social identity and the actual social identity. It is a social phenomenon in which the stigmatized individuals are considered 'others,' possibly as not quite human. It is strongly influenced by the assignment of responsibility or blame for the condition by the stigmatizer.

However, stigmas are not all equal. For example, the stigma based on illness may be less for those with conditions that are well understood, such as heart disease, than for those with conditions that are less well understood or less controllable, such as epilepsy or AIDS. Stigmatization may be proportional to the sympathy for the affected individual or the responsibility assigned to the individual for the illness (Rothschild, 1970).

HIV-infected women experience discrimination from many fronts. Besides their HIV infection, they can attribute discrimination to their minority ethnicity, their perceived sexuality, and their socioeconomic status. When the HIV-positive woman also has an

infected child, add the stigma of being a carrier infecting the innocent. The interrelationships of these characteristics form the basis of the stigma reported by the HIV-positive mothers in this study.

Reactions from Others

The experiences of the mothers in the current study are congruent with other reports of stigma experienced by other HIV individuals and families (Bunting, 1996; Goldin, 1994; Moneyham et al., 1996a; Weitz, 1990). These families reported overt behaviors of (a) discrimination, rejection, and ostracism by family and/or friends as well as religious and/or health care professionals and (b) being associated with drug use and promiscuous sexual lifestyles whether or not that was the case. Mothers in the current study identified subtle behaviors of stigma reported by other HIV-positive women (Moneyham et al., 1996a). These included stigmatization through distancing (maintaining a physical distance from the infected individual); overgeneralizing (presuming drug use or prostitution by the infected person); and social discomfort (acting uncomfortable around them but pretending HIV infection does not bother them).

Experiencing Triple Stigma

Reports of HIV-infected individuals confronted with a *double stigma* (Laryea & Gien, 1993) inspired the original basis for this concept. Hemophiliacs described the concept of a double stigma as suffering the stigma of HIV infection in addition to the stigma of risk groups (high risk sex and/or drug use) associated with HIV. Even though they did not belong to such risk groups, such as injection drug users, gay men, or having multiple sexual partners, they felt stigmatized by the presumption that they must belong to

one of those risk groups. From their stories as HIV-positive mothers with HIV-positive children, the concept of *experiencing the triple stigma* of HIV disease emerged.

The mothers in the current study reported suffering the stigma of HIV infection previously reported by other HIV-infected individuals. This stigma is associated with HIV being a contagious, fatal disease and with HIV being discriminate, that is, those who deserve it are the ones who get it (Herek & Capitanio, 1993). Individuals, such as hemophiliacs, feel the stigma of guilt by association, that is, because they have HIV, they must be drug users, gay, or promiscuous.

To this concept of double stigma, add the stigma of infecting the innocent, an unborn child. Nearly three-fourths of the mothers felt this stigmatization was most evident in the health care setting. They reported that physicians and nurses repeatedly asked how they became infected when the information had no bearing on any aspect of their care. Mothers believed that the mode of HIV transmission would influence the care provider's attitudes toward them. They felt that injection drug users would likely be blamed for infecting their child and thereby elicit a hostile reaction, whereas a woman unknowingly infected by her husband would more likely elicit a sympathetic response from care providers. Consequently, mothers who have perinatally infected their children may experience a *triple stigma*.

Strategies to Manage Stigma

Edgerton (1967) identified methods used by the stigmatized individual to manage stigma as: *denial* (the explicit rejection of the stigmatized identity) and *passing* (the attempt to present oneself as normal). Following the contention that denial is associated

with the subconscious blocking out of emotional experiences (Hymovich & Hagopian, 1992), the experiences described in the current study did not support the use of management by denial by this group of mothers. Instead, their strategy appeared to have been to use *suppression*, defined as a conscious decision to delay facing an unwanted conflict (Hymovich & Hagopian).

They applied suppression of the diagnosis when there was no need to disclose, thereby deferring the time when mothers might have to face stigma resulting from disclosure. When the HIV diagnosis was known to others, mothers with HIV-related symptoms used the strategy of *passing*. Mothers could reduce the potential for stigma by *passing* their symptoms off as non-HIV-related, such as attributing recurrent pneumonias to 'weak lungs from asthma' rather than to decreased immunity to bacterial infections. Mothers in this study also used *passing* to manage stigma by taking the innocent victim approach when disclosing. For example, when one mother disclosed her infection, she passed herself as infected through a blood transfusion, rather than her previous injection drug use.

Finding Out the Diagnosis

The mothers in this study identified three primary experiences related to *finding out their HIV diagnosis*: (1) the timing of the diagnosis in relationship to their pregnancy, (2) their emotional reactions, and (3) their behavioral reactions. The following discussion will present a summary of this study's findings and its significance to the current research.

Timing of Diagnosis

The timing of the HIV diagnosis and its relationship to the pregnancy had different

implications dependent on whether the diagnosis was made before the mother became pregnant, while she was pregnant, or after the child was born. Two mothers who knew their diagnosis before their pregnancy faced issues of whether or not to have any children and had decided not to bear any children. They described their subsequent pregnancies as unplanned, but not unwanted.

Mothers diagnosed in the first trimester of pregnancy faced the decision whether to continue or end the pregnancy. They reported influencing factors to continue the pregnancy as the advanced state of the pregnancy and their moral or religious beliefs. Factors influencing their decision to end their pregnancy were primarily feelings of being pressured by their physician to abort. Mothers diagnosed because of the child's diagnosis either at birth or early childhood identified issues of facing their HIV diagnosis, changing family relationships, and making decisions about treatment.

This study supports findings from Williams (1990) whose sample of women were either HIV-positive or at risk for HIV infection (injection drug use or sex with a partner with injection drug use). Their sample identified central issues related to being diagnosed during pregnancy as (a) ending the pregnancy and (b) realizing that they may die. Like the mothers in the current study, most agreed that abortion was the correct decision for an HIV-positive pregnant woman, although none of the pregnant women in either study had an abortion.

The HIV-positive mothers in the current study reported many of the same factors influencing their reproductive decision-making. Both groups identified factors influencing their decision to continue their pregnancy as (a) a personal morality, (b) desire for the

child, (c) the advanced state of their pregnancy, and (d) their religious faith. Both groups also identified factors influencing their decision to terminate their pregnancy as (a) their desire to avoid the stigma of having HIV for the child and (b) counseling promoting termination.

Findings of the current study also supported the previous findings of a study of HIV-positive women with a history of injection drug use (cited in Nokes, 1992) who discussed factors influencing their decision to continue their pregnancy. These mothers did not report their own health or concern about AIDS as reasons for an abortion. They cited the most important reasons for continuing the pregnancy was their desire for a child and their religious beliefs. Mothers in this current study also identified factors influencing their decision to continue their pregnancy as their moral or religious beliefs, although some also reported feeling pressured by their physician to terminate.

What did not emerge from the data of the current study, however, was the relationship between diagnosis during pregnancy and delayed entry into health care for HIV-infected women reported by Ickovics, Forsyth, Ethier, Harris, and Rodin (1996). They reported that women who learned their HIV status during pregnancy, women with low socioeconomic status (SES), and women of color were more likely to delay their entry into care when compared to women who had moderate SES or were white. There was no difference in delayed entry on the basis of whether the woman was infected through injection drug use or heterosexual contact. Although the current study did not apply the same analytical process as Ickovics et al., none of the HIV-positive mothers diagnosed during their pregnancy reported delaying seeking HIV treatment or prenatal care following their diagnosis.

Reaction to Finding Out

Crisis points identified across other life-threatening illnesses occur with AIDS as well (Nichols, 1985). The reactions reported by the mothers in the current study support the early findings by Nichols (1985), adapted by Grimes and Grimes (1996), and similar recent findings by Mason, Preisinger, and Donohue (1995) that an HIV-infected individual experiences reasonably predictable psychological states. Both researchers present progression through HIV disease in a four stage psychosocial model. Both models present the first stage as an initial confrontation or crisis period of diagnosis; the second as a period of transition or adjustment to the illness; the third reflects the period of clinical events indicating disease progression; and the final stage as preparation for the end of life.

For the mothers in the current study, time from diagnosis ranged from eight years to two years. Although none of the mothers were in the immediate post-diagnosis period, all could clearly articulate their emotional and physical reactions when they found out they were infected. Most of the mothers fell in the second and third stages of adjusting to the illness or experiencing clinical symptoms; one mother was nearing the end-of-life state.

The findings in the current study support the psychological and psychosocial reactions reported by both of the previous researchers. They describe the discovery of being HIV-positive as characterized by affective numbing, disbelief, and denial alternating with intense anxiety. Increased risk of suicide has also been associated with HIV antibody testing and learning of a seropositive status (Flaskerud, 1992). The period following diagnosis where individuals struggle to make sense of the illness and confront the physical reality of the disease may be so overwhelming as to induce depression and suicide or suicide ideation as well. The next stage often coincides with the onset of symptoms that are either unresponsive to current treatment or require new treatments. The final state is the preparation for death where feelings of guilt, depression, or spirituality may be exacerbated (Mason et al., 1995) while fear of dependence, loss of control, or pain may lead to suicide ideation or suicide (Flaskerud, 1992; Grimes & Grimes, 1996).

Generally the mothers in the current study exhibited similar emotional and behavioral characteristics presented by Nichols (1985) in his four state psychosocial model of the experience of the HIV-infected individual moving. They reported feeling shocked, devastated, and overwhelmed at their diagnosis similar to the feelings of disbelief and numbness reported by Nichols and Mason et al. Interestingly, nurses infected through occupational exposure also described initial reactions to the diagnosis as shock and disbelief, anger, and feeling overwhelmed by emotion (Newton, 1995). The findings from the current study and previous research suggest that the states of HIV infection concept proposed by Nichols and Mason et al. that the initial emotional reactions (shock, disbelief, anger, depression, and suicide ideation) occur as a result of the HIV diagnosis independent of individual or group characteristics.

Self-destructive behaviors, such as substance abuse or unhealthy sex practices, have been categorized as expressions of denial or anger (Mason et el., 1995). The study mothers described emotional and behavioral characteristics of depression as they faced the reality of HIV infection. Several of these mothers did turn to alcohol or drug use as a direct response to their diagnosis although the data analysis cannot attribute such behaviors to their feelings of anger or denial. The increased risk of suicide associated with this time of diagnosis was, unfortunately, exemplified by the suicide attempt by one mother in the current study.

Most of the mothers reporting HIV-related symptoms described their health as good to very good although not all followed a prescribed course of treatment. While Mason et al. reported HIV-infected individuals to be at high risk for increased drug use or risky sexual practices, none of the mothers in the current study reported either behavior. Instead, the mothers reported that their children were primary motivators for maintaining their health.

Moreover, one mother in the end stage of her illness described herself only as being in 'very poor health'. Clinically, however, this mother had total kidney failure requiring dialysis; chronic pancreatitis with weight loss of over 100 pounds in six months; chronic diarrhea; and severe neuropathy in all extremities. She spoke about dying in an offhand manner, as if it were a distant event. Her primary concerns were how to address her HIV-positive daughter's fear that the mother would die someday. Both Mason et al. and Grimes and Grimes characterize the final stage of the illness as an egocentric time where the patient's awareness of dying underlies their emotional and behavioral responses. Clearly in the end stage of her illness, this mother's experience suggests that this period of patient awareness may have a small window or that the patient may not express their awareness of dying as it relates to themself (i.e. *their* guilt, *their* regrets, *their* bargaining), but rather that their awareness of dying may be evident only through their concerns of the impact on others.

Effect on Family

Mother: Self-Identity

Mothers in this study, for whom their HIV-positive child was their only child, struggled to achieve a *preferred* identity of a *contingent self*, a potential role made uncertain due to the illness. These mothers described their struggles with wanting to be 'mothers,' but not being able to perform some basic mothering behaviors (such as breastfeeding) they felt defined the role of 'mother.'

The experiences of the mothers' attempt to maintain their identity reflected what Charmaz (1987) described as developing a *preferred* identity of the *restored self*; that is, the identity before the illness. Mothers who had other children described their desire to keep their previous identity as 'mother' rather than become 'the person with AIDS.'

One mother in the current study expressed her desire to have her daughter remember her in a positive light due to the stigma associated with HIV/AIDS. This mother, infected by her partner, participated actively in volunteer organizations and worked with youth groups to increase their AIDS awareness. She planned to videotape some of her activities so that her daughter would remember her as a caring person and loving mother and not 'the person who gave her AIDS.' Charmaz characterizes this as *preservation* of one's identity, the quest to give one's life meaning, to immortalize oneself. This study's findings support similar findings reported by Black et al. (1994) whose HIV-positive mother respondents decribed the importance of taking care of their children. Like the mothers in the current study, the Black et al. respondents described the importance of caring for their children and of having their children remember them with pride.

The Mother-Child Relationship

The nature of the mother-child relationship described by the mothers in the current study support the findings from two studies of HIV-positive mothers with a seropositive child (Andrews et al., 1993; Cohen, Malm, Nehring, & Harris, 1995). In those studies, mothers characterized their relationship with their HIV-positive child or their other children as a special relationship in which the child was a source of support for the mother, providing affection and decreasing the mother's sense of isolation. The mothers in the current study reported similar experiences with their children and even reported some as young as five years old assuming a protective role that included comforting or reassuring the mother as well. The current study also supported the Andrews et al. findings that the children oftentimes provided the positive support needed to prevent mothers from engaging in high-risk behaviors, such as drug and/or alcohol use.

Moreover, Cohen et al. (1995) reported some mothers were reluctant to leave their children, even with competent caregivers, wanting to spend all the time possible with her child. However, the researchers suggest that this may change as the mother becomes more symptomatic, thus requiring respite time. The findings from the current study further suggest that uncertainty of the illness course may make mothers reluctant to leave their child due to the fear that the child might become critically ill or die in her absence.

Andrews et al. (1993) also categorized the mother/child relationship as burdensome, citing maternal concerns regarding placement of surviving children, anxiety over illness course, lack of privacy, lack of childcare, and negative reactions from their children. While the mothers in the current study described similar experiences, it was not evident to this researcher that the mothers perceived these experiences as burdensome.

Another finding that emerged from a study of HIV-positive mothers (child's serostatus not reported) characterizes children as the source of feelings of helplessness and self-blame (Frank et al, 1995). However, the report findings by Frank et al. do not describe the context of feeling helpless or self-blame beyond reporting that "children are the source" (p.118) of those feelings. Consequently, while helplessness and self-blame were emergent concepts in the current study as well, that alone cannot support the Frank et al. findings as reported.

HIV-positive Mother-Spouse/Partner Relationship

Of the ten HIV-positive mothers either married or living with a partner at the time of diagnosis, seven had divorced or separated as a result of the women finding out that the partners or spouses already were HIV-infected.

Effect on Family Relationships

In their descriptions of the effect of their HIV infection on family relationships, the mothers in this study described similar experiences reported by other HIV-positive groups (Laryea & Gien, 1993; McCain & Gramling, 1992; Rose, 1993; Wachtel, Piette, Mor, Stein, Fleishman, & Carpenter, 1992). The findings of this study support published research findings that (a) HIV-positive women generally often only told their own mother initially, (b) support or rejection within families varied, (c) family members in frequent contact who lived nearby were usually told, and (d) all respondents reported rejection by some family members. This study also supports the finding by Wachtel et al. (1992) that when family members were told, those with small children most often rejected the HIV-positive individual. While Laryea & Gien (1993) reported that some family relationship disruptions were precipitated by the moods of the infected individual, two mothers in the current study reported that it was their return to injection drug use that caused the family to 'turn away' from them.

The current study provides additional, although limited, insight into the effect of HIV infection on family relationship not currently available in the research literature except as anecdotal case reports. This study examined the family relationships from a somewhat ecological perspective; that is, from those family members identified by the mother as having the closest, most frequent contact with her to those on the periphery with whom the contact was considered infrequent and more formal, but still valued.

Some recurring themes were identified about the impact of HIV /AIDS on the family relationships of the HIV-positive mothers in this study. Mothers and sisters provided the primary support for the HIV-positive mother in the period after her diagnosis, while sisters were identified as the primary support person thereafter. Sisters were also the most likely to care for the HIV-positive child after the mother's death. Sisters were the primary support person for the mothers in this study. Although they were more likely to turn to their own mothers in the immediate post-diagnosis period, sisters were identified as being the primary support thereafter and were most likely to care for the HIV-positive child if the mother died. In some instances, a younger sister (uninfected) reversed roles with the older HIV-positive sister and assumed the 'big sister' role.

All mothers looked to family members, whether immediate, extended, or distant, for potential support. However, grandmothers and other elderly relatives, regardless of frequent contact with the HIV-positive mother and child, were not likely to be told of the HIV diagnosis. Mothers did not look to the father of the HIV-positive child for emotional, physical, or financial support. The prohibitive cost of medication and medical care required mothers to rely on MediCal rather than seek financial assistance from the fathers of the HIV-positive child. Mothers frequently relied on family members for financial assistance or food.

Generally, those relationships that were close prior to the HIV diagnosis, remained close; those that were distant, remained distant. The HIV diagnosis offered little motivation for reconciliation of previously damaged relationships.

Blame

Blame has been identified as a major psychological or emotional stressor for the HIV-positive individual. Assignment of blame for HIV/AIDS have been directed toward groups already stigmatized or marginalized, such as homosexuals, injection drug users, prostitutes, and ethnic minorities. Nearly 20 percent of white and African American respondents in one study believed that gay men and injection had "gotten what they deserve" (Herek, & Capitanio, 1993, p. 576). Persons with AIDS not associated with any of those groups have been described as innocent victims, such as hemophiliacs, perinatally-infected children, and unsuspecting wives or partners of HIV-positive men. If these persons are innocent, then the further implication is that those who infected them must be considered responsible, or to blame, for their infection.

The experience and feelings of the mothers in the current study are congruent with previous research with mixed samples that identify blame as a significant part of the HIV-positive individual's experience (McGrath, 1992; Herek & Capitanio, 1993; Goldin, 1994; Johnson & Baer, 1996). Research into the experience of HIV infection for HIV-positive women in general or HIV-positive mothers in particular has alluded to the existence of blame either as self-blame or being blamed (by children) (Cohen et al., 1995; Frank et al., 1995).

This study supports the general findings of current HIV+women's research by identifying blame as a major part of their experience, but adds the dimensions of who mothers felt they were being blamed by and the context in which the blaming occurred. It identified that not only are HIV-positive mothers blamed by others, they blamed themselves and each other as well. Infected mothers described mothers with drug-related risk behaviors as 'more to blame' for their child's infection than mothers who had been infected by partners. Infections through injection drug use were referred by mothers as 'dirty' infections.

The current study provides a closer look at the experience of blame at the different levels of interaction in which it is experienced by the HIV-positive mothers. Until there is further research in the area, however, it will not be known whether these experiences are unique to the infected mother-child dyad or to HIV-positive women in general.

Feeling Helpless

Seligman (1975) proposed a theory of learned helplessness in which he presented helplessness as a learned condition. He suggested that people learn helplessness when they experience a noncontingent relationship between response and behavior; that is, the chances of something happening are independent of what the person does. Helplessness occurs following repeated exposures to uncontrollable events. The extent to which people perceive they have no control (due to their lack of skill or to external factors) contributes to their sense of feeling helpless (Abramson, Seligman, & Teasdale, 1978).

The experiences in caregiving described by the mothers in this study reflect the basic tenets of Seligman's theory of learned helplessness. First, no relationship existed between the illness outcome and care given. The HIV-positive mothers did not relate positive outcomes for acute episodes of HIV-related illness to their diligent nursing care nor conscientious medication or treatment administration. Consequently, the HIV-positive mothers felt helpless to prepare her children for subsequent episodes of illness or to give them any hope that the course would be less severe. Second, recurrences of illnesses they could not control left the mothers feeling helpless to help their child. Further, HIV-positive mothers reported that their lack of knowledge and the uncertain disease course made them feel helpless to select the best treatment and thereby alter or ease the course of the illness.

The experiences of the mothers in the current study support the findings from Frank et al. (1995) who investigated feelings of *helplessness*, *anger*, and *being scared* in his sample of HIV-positive women (n=32) of which twenty-one were mothers (serostatus of children not reported). Living in urban areas, being African American or Hispanic, and having children were characteristics of the HIV-positive women reporting helplessness in the Frank et al. group. These characteristics were similar to the general demographics of the current study group who described experiences of *feeling helpless*.

Hope

Hopefulness

Miller and Powers (1988) describe three levels of hope: (1) superficial wishing, such as for a pleasant day or basic material goods; (2) personally directed, hoping for self-improvement, self-accomplishments, and relationships; and (3) relief-focused, hoping for relief from suffering, personal trial, or entrapment. Stoner (1988) poses two views of hope in the face of a terminal illness. The first view holds that hope is appropriate only if it is realistic. The implication is that hope may be conceived as unrealistic as well, a perspective held by other researchers (McGee, 1984; Hinds, 1988). The second view holds that hope maintains emotional well-being in the face of both ordinary and dire circumstances and so always has positive value.

Hope differs from the intrapsychic activity of wishing. In wishing, the person desires something but does not have the expectation that it *must* happen. In hoping, the desire is more intense with the expectation that the event *must* happen. This distinction between ***hoping*** and ***wishing*** has been discussed in the literature (Hymovich & Hagopian, 1992; Korner, 1970) and, for clarity, such distinction will hold for the following discussion as well.

In HIV-positive women or HIV-positive mothers research, hope has been mentioned briefly either as a general finding as an emotional or psychosocial response to HIV infection (Cohen et al., 1995) or not at all (Frank et al., 1995; Williams et al., 1993). Consequently, the concept of hope, as persons with HIV have experienced it, has emerged from research with primarily HIV-positive men who were asymptomatic (Hall, 1990;

Taylor, 1988) or had AIDS (Hall, 1994).

The experience of the HIV-positive mother in this study supported the Millers and Powers (1988) conception of hope having three levels. Some mothers wished they could give their child simple things, such as going to McDonald's or renting movies. For themselves, more than half hoped to have a relationship with a partner, preferably HIV-positive, in the future. However, all mothers hoped for relief from suffering for their children. The only mothers who also wished for relief for themselves were the two mothers with chronic diarrhea.

The hope for relief from their HIV infection was expressed in two ways: hope for a cure and hope for better treatments. The findings of this study support a distinction of the mothers' hope based on the desired outcomes rather than on a judgment of being realistic or unrealistic. Because the mothers' hopes are grounded in their experience as an HIV-positive mother whose child is also infected, she must define her reality of that experience. Consequently, she must make any judgment of what is realistic or unrealistic. Therefore, they accept that the mothers in this study expressed hope for the best possible outcome for their child based on *what they believed* to be realistic.

Some mothers hoped for the best possible outcome, the *optimal outcome*, for any life-threatening illness; that is, a cure or a miracle. Mothers often used prayer while hoping for this outcome. Several mothers used the term 'realistic hope' to describe their hopes for their child. Mothers defined their *realistic hopes* as hoping for better treatments to ease the symptoms of opportunistic infections or to slow the disease progression toward AIDS.

Hopelessness

Hopelessness is said to occur when the person believes that nothing can be done to change a situation, does not feel worthy of help, or has feelings of giving up (Engel, 1968). As with hope, hopelessness has generally been addressed as a consequence of HIV disease.

The mothers in the current study attributed their sense of hopelessness to their inability (or perceived inability) to defeat or alter the disease course for themselves or their children. Mothers identified their physicians and therapists as the factors influencing their sense of hopelessness. Without hope, mothers did not see the need to change self-destructive behaviors, such as smoking, excessive alcohol and/or drug use, adopting a 'Why bother?' attitude.

Disclosure

The major category, *disclosure*, and the identified subcategory, *deciding to tell*, have been identified by the mothers in this study as a critical part of their experience as an HIV-positive mother whose child is also seropositive.

The HIV-positive mothers in this study shared similar concerns and experiences with other HIV-positive women overall, and HIV-positive mothers in particular, regarding disclosure of their HIV status. For the mothers in this study, issues of temporality, rejection, even physical harm emerged as major concerns for the HIV-positive women. Temporality issues for the sample concerned timing of disclosure to children and their siblings. For these mothers, the further issue was whether to disclose to day care or

schools without disclosure to the HIV-positive child and/or the siblings. The mothers' major strategy was to take the 'wait and see' approach.

The HIV-positive mothers in the current study, as did HIV-positive mothers in previous studies (Moneyham et al., 1996; Plishkin, Farrell, Crandles, & DeHovitz, 1994), agreed that they should tell their children at some point. However, all three groups indicated that the children were too young to tell. For the HIV-positive mothers in the current study, 'too young' referred to the developmental stage of the child whereby the children could not keep a secret (thus risking exposure) nor understand the physiological and social implications of the disease. Mothers in the current group, like the mothers in Moneyham et al., were reluctant to disclose their own diagnosis to anyone, fearing that the children might find out their own diagnosis from someone else.

Moreover, the HIV-positive mothers from all the studies expressed the desire to preserve their child's childhood, wanting them to be 'a child as long as possible.' Mothers who were asymptomatic wanted to preserve their pre-illness identity for as long as possible as well.

For the HIV-positive mothers, however, the child's 'ability to understand' was their marker for timing of disclosure, which they estimated to be 'at least ten years old.' Interestingly, their estimation of ten years as a marker for disclosure coincides with the child's transition from concrete operational thinking to formal operational according to the Piagetian theory of cognitive development (Whaley & Wong, 1991). According to this developmental theory, the thought processes of children at this age become more socialized; that is, less self-centered with increasing flexibility to consider points of view other than their own and consider impact on others. It was at this level of development that mothers felt their child would be able to under the physiological and psychosocial facets of HIV infection which, in turn, would affect the child's decision making regarding disclosure.

The experiences of the HIV-positive mothers in this study and reported findings from research in 1994 and 1996 continue to identify fear of stigmatization as a major concern affecting disclosure to children (Moneyham et al., 1996a; Plishkin et al., 1994). The fear of stigmatization for all groups was based on perceived as well as actual experiences with negative reactions from others, including health care professionals. Moreover, some parents of the HIV-positive mothers requested they not disclose their diagnosis. When they received this *external input*, the HIV-positive mothers in the current study did not disclose. Findings from the previous studies, supported by the current findings, substantiate that children experience negative responses and, therefore, are not exempt from the stigmatization associated with HIV disease.

Further, mothers in the current study identified additional concepts related to *deciding to tell* their diagnosis (or their child's) as (a) external input and (b) the need to know. *External input* was generally a request from a close family member not to disclose. When so requested, none of the mothers disclosed their own or their child's HIV disease.

Mothers assessed the disclosee's *need to know* when deciding whether to disclose. The basis of the *need to know* was an assessment of the risk of transmission to others and of the health care needs for her child or herself. The focus of assessing the need to know generally involved childcare or school settings. Mothers were almost evenly split between disclosing and not disclosing to the program administrators. All mothers feared the risk of exposure to be great. In these settings, mothers who decided to disclose were influenced by the child's needs. For example, some children required medication during day care or school hours, while others required extra consideration from teachers or caregivers to manage symptoms such as diarrhea, nausea, or decreased energy. Mothers who were unsure continued to balance transmission to others and health care needs against the risk of exposure. One mother, whose child was six years old, had not decided whether to even enroll her child in school.

Coping

Coping is not a static process. Rather, it changes according to the demands of the situation and the individual's perception of the situation. The findings of the current study have described HIV illness as a stressful situation for all HIV-infected individuals that crosses the medical and psychosocial aspects of the disease. HIV-positive mothers with seropositive children have identified stress related to the diagnosis, uncertain disease course, lack of supportive relationships, and the threat of both mother and child dying.

One purpose of the current study was to identify strategies to manage the experience of being an HIV-positive mother with an infected child. Recent studies have attempted to identify, measure, and/or correlate coping behaviors of HIV-positive mothers (Hardy et al., 1994; Hutchinson & Kurth, 1991; Mellins & Ehrhardt, 1994; Rose & Clark-Alexander, 1996). The means of coping identified in the current study reflect strategies used by individuals to manage their illness within the context of HIV/AIDS.

Folkman and Lazarus (1980) organize the two major functions of coping into problem-focused coping and emotion-focused coping. Problem-focused coping refers to actions taken to remove or alter the source of stress, while emotion-focused coping attempts to reduce or eliminate the emotion distress associated with the stressful event (Folkman & Lazarus, 1980). Some strategies are shared; that is, they serve to address both the physical and emotional aspects of the stressful event.

Problem-Focused Coping: Managing the Illness

Mothers reported major stressors related to their child's infection as: not knowing what to expect of the disease course; what treatments to select and to stop; being sick and being the primary caregiver; and wanting to maintain normalcy. Strategies for managing these aspects of their HIV illness fell into four categories: *maintaining health*, *managing/prioritizing needs*, *performing skills*, *seeking information*, and *maintaining normalcy*. Because *seeking information* and *maintaining normalcy* also serve as emotion-focused strategies, they are discussed in the final category: shared strategies.

Mothers recognized the need to optimize their health so they could perform the responsibilities of primary caregiver for themselves, their HIV-positive child, and other children living at home. Mothers identified changing behaviors to enhance ***maintaining health***. Behaviors that they eliminated or modified included drug and alcohol use. However, they did not modify cigarette smoking behavior unless they experienced chronic or acute respiratory infections. Mothers adjusted diets for both them and their children to control episodic or chronic diarrhea. In addition, mothers kept a strict adherence to drug treatment regimens. Equal emphasis was placed on alternative therapies, such as Chinese herbs, massage, and acupuncture.

Mothers developed strategies to manage and set priorities for short-term and long-term needs. Most mothers adopted a living-one-day-at-a-time perspective to manage the physiologic course of the illness. This allowed them to manage the unpredictability of the disease course by maintaining vigilance over their health and focusing on complex daily treatment regimens for both mother and child. They also applied time conserving tactics, such as budgeting time for treatments, streamlining household procedures, and consolidating activities.

Skills needed to manage the illness were learned through experience. The ability to *perform the skills* required to care for their child was needed, but difficult to obtain. Mothers felt unsure about caring for their child with feeding tubes, intravenous catheters, and other devices. Mothers eventually became accustomed to these aspects of care, but would have preferred to have learned the skills beforehand.

Emotion-Focused Coping: Managing Emotional Distress

Coping with their HIV illness also included *managing the emotional distress* of their illness. Emotion-focused coping was directed at managing the stress and anxiety from having the dual HIV-infection of mother and child. Strategies included *seeking support*, *maintaining hope*, and *seeking meaning for the illness*. The combination of strategies used by the mothers varied by their own philosophy and the state of their infection.

Mothers sought support family, friends, and resource groups to help them cope with the emotional burden of being an HIV-positive mother of an HIV-positive child. Although mothers actively sought groups with HIV-positive mothers with seropositive children, their assessments of the effectiveness of such groups were mixed. Some mothers who did not find such groups helpful support the findings of DiPasquale (1990) that reported no significant improvement in anxiety and hopelessness in minority women support group participants. The mothers in the current study felt that attachment to and subsequent loss of support group members increased their feelings of anxiety and hopelessness to the point where they no longer participated in support groups. Mothers in the current study who found such groups helpful reported the ability to find resources as the main reason. However, the characteristics of the mothers in the current study who found groups helpful and those who did not vary. Mothers who did not find the groups helpful characterized their own health as extremely poor to good and reported more HIV-related illnesses and/or chronic problems such as diarrhea and yeast infections. Mothers who found the groups helpful characterized their health as good to very good, with few HIV-related symptoms.

The difference between the two groups suggests that the worth of HIV support groups may be related to the need of the individual. That is, the HIV-positive mother who is showing signs of disease progression may be forced to face issues of dying if she sees them as a reflection of her future. On the other hand, mothers who are not showing signs of disease progression may not identify with the symptomatic members of the support group. Their focus may be to maximize their resources to learn about the disease rather than treatments or current clinical trials. However, the current study findings are not sufficient to draw such conclusions, and rather serve to suggest areas for future research.

The reality of HIV disease is the disease has a downward physical course. However, *maintaining hope* is one strategy to cope with this reality. Mothers in the current study identified strategies for *maintaining hope* as believing in a cure or miracle, using spirituality as a source of hope, surrounding themselves with family and friends with positive attitudes, and doing positive things, such as community service. The findings of the current study reflect strategies reported in research with asymptomatic HIV-positive men and men with AIDS (Hall, 1990, 1994).

The *search for meaning* of the illness is not unique to those with HIV/AIDS. Any injury or life-threatening illness invokes the question of "Why me?" in an attempt to understand the perceived inequity of their situation. In this study, the mothers infected by their partners presented this perception of inequity. These mothers reported anger and frustration in trying to discover the rationale for their illness, especially HIV infection. Most of the mothers identified spiritual causation, such as God wanting them to be examples so they could save other lives. One mother, diagnosed following her husband's AIDS diagnosis, felt that having HIV disease had no special meaning and causation was as indiscriminate with HIV as with cancer. Overall, mothers who attributed meaning to their illness reported participating in activities that complemented that meaning. For example, one mother believed the purpose to her infection to be her opportunity to increase others' awareness of AIDS. She worked with youth groups in AIDS awareness activities or other activities that helped her fulfill that purpose.

Several mothers who had been infected by their spouses continued to struggle with finding meaning. They expressed frustration and anger in their lack of understanding why they 'had been chosen.' They expressed their feelings of injustice at having HIV/AIDS as being greater than if they had developed cancer. Some mothers prayed to gain understanding, but most continued to feel angry at having been infected.

Shared Strategies for Both Problem-Focused and Emotion-Focused Coping

Some strategies served to manage both the physical and emotional aspects of the illness. For example, *seeking information* increased their cogntive knowledge about HIV infection and, in doing so, decreased some of the intensity of their anxiety or uncertainty. In *seeking information,* mothers used various resources. Some mothers attended the classes offered by a local HIV center for women, learning about opportunistic infections, current clinical trial results, and alternative therapies. Mothers actively sought to network through various HIV centers to broaden their scope of resources.

Another strategy, *maintaining normalcy*, allows the family to acknowledge the effects of the illness, while denying its social significance (Knafl & Deatrick, 1986). Charmaz (1991) reported that persons may even normalize chronic symptoms, such as discomfort, pain, or fatigue. For the mothers in the current study, *maintaining normalcy* focused on their efforts to preserve their well-role identity. With the use of *suppression*, the conscious decision to delay facing an unwanted conflict, mothers in this study could preserve their well-role or their pre-HIV identity. Preservation of their preferred identity allowed them to distance themselves and their children from the stigmatization of their HIV infection.

Summary

This study attempts to increase understanding of the mother's experience of having herself and her child infected with HIV by presenting the HIV-positive mother as situated in diverse, but interconnected, relationships at multiple levels of interaction. At a time when the diagnosis dealt a devastating blow to her and her child, she found herself facing a future marked by stigmatization, rejection, and fear from others, where the only thing certain was that the disease is uncertain. Most were mothers attempting to raise their children with minimal resources that may be further compromised by being the primary caregiver for herself, her child, and perhaps even a spouse or partner with HIV/AIDS. There may have been the added stress of substance abuse, either her own or family members. From the time of her diagnosis, she managed her own and her young or unborn child's care. Treatment decisions had to be made for a disease she was afraid to tell anyone she had, thus limiting her ability to seek appropriate resources or support. She faced the dual impact of blame: blaming herself as well as being blamed by family, health care professionals, even other HIV-positive mothers. Compounding the emotional issues of blame, they often felt helpless to help their children, much less themselves. However, most mothers maintained hope for either a cure or improved treatments, but remained cognizant of the fatal nature of their disease. Exposure remained an overriding fear for the mothers and the fear of stigmatization impacted all aspects of disclosure: when to tell to the child, fear of negative reactions from others, desire to maintain a well-role identity, and when and why to tell to others. She faced the threat of the triple stigma of HIV: having a lethal, contagious, feared disease; being associated with drug and sexual risk behaviors; and being a carrier infecting an innocent victim, her child. Within that context, she struggled to establish, maintain, and preserve her identity as a mother.

Finding out the diagnosis was overwhelming to the mother, despite the mode of transmission. Mothers who knew that their sexual or drug use behaviors were associated with HIV transmission were equally 'shocked and devastated' as mothers who were infected by spouses or partners. Some mothers did not believe the initial diagnosis for themselves or their child and retested. Almost all faced a period they characterized as extended periods of crying, inability to perform daily activities, or even say the diagnosis aloud. Mothers also reported that finding out the diagnosis was their impetus to enter drug or alcohol recovery programs so that they could care for the HIV-positive child. Others who had completed such a recovery program relapsed under the stress.

If she was diagnosed before or during her pregnancy, women faced decisions of future pregnancy or continuing the current pregnancy. While most mothers advocated termination of pregnancy as an alternative, those diagnosed early in their pregnancy did not do so. Three factors influenced their decisions: the advanced state of the pregnancy, the pressure from medical staff, and their religious or moral beliefs.

Some former sources of support, close friends and family members, disappeared. If others perceived the mother's self-responsibility for the disease as high, she found herself ostracized, alone at a time when both emotional and physical support were critical. It was difficult to predict the reaction from others with HIV disease and so mothers feared telling anyone, some keeping the secret and others denying the infection. Both circumstances resulted in isolation and the lack of appropriate care.

She felt a strong bond with her special child, maximizing their time together and trying to look to a future, any future, long or short term. However, when the HIV-infected child was the only child, mothers felt as though they had no time to develop their identity as a mother. Instead, their role became 'dying mother with a dying child.' If the mother had other children then the emphasis was the need to maintain normalcy by maintaining their identity as 'mother' rather than 'person with AIDS.' When some mothers faced the reality of predeceasing her child(ren), they wanted to preserve an identity as mother; that is, they desired to be remembered by the child as 'mother' rather than as 'the person who gave them AIDS.'

HIV-positive mothers experienced a dual phenomena of blame: being blamed or blaming. They felt blamed by health care professionals who presumed they had been infected through sexual or drug use behaviors. Mothers ascribed blame to other HIV-positive mothers as well, referring to the mothers infected through sexual or drug use risk behaviors as 'dirty infections.' Both mothers who did engage in such risk behaviors and those who did not (infected by partner) blamed themselves either for their risk behaviors or for the relationship that led to infection. Mothers who did not attribute their infection to knowingly participating in high-risk behaviors searched for meaning for their disease, often angrily, looking to God for explanation. Those who could attribute a purpose to their illness, such as saving others from AIDS, participated in activities directed to achieve that purpose. Those unable to attribute purpose for their illness continued to turn to God for meaning, often angrily.

Most mothers felt helpless at some point during their illness. The unpredictability of the disease course made them feel helpless to anticipate and thereby prepare themselves, their infected child, or the siblings for opportunistic illnesses. They could not reassure their child or the siblings that the child would get better or even come home from the hospital. They were helpless to alter or ease the only predictable aspect of the illness, its fatal outcome.

Hopefulness, as well as hopelessness, permeated the experience of the HIV-positive mother-child dyad. Mothers hoped for a realistic outcome: better treatment to ease symptoms or slow disease progression. They also hoped for the optimum: a cure or a miracle. The death or dying of their child or friends from HIV infection brought the reality of the fatal nature of their illness to the forefront and increased a sense of hopelessness in the mothers. Comments from physicians and therapists regarding AIDS and death as the ultimate outcome for HIV infection further increased that sense of hopelessness.

Fear of exposure and its consequences was the major deterrent to disclosure by any HIV-positive individual, and it was no less for the HIV-positive mother. Their decision not to tell others was influenced by their perceived or actual negative experiences in disclosing, their desire to maintain a well role identity, and requests from family members not to tell. However, if they perceived a risk of transmission to others or they required medical care (for mother or child), mothers generally disclosed their seropositive status. Some, however, continued to struggle with the consequences of exposure versus the need for others to know. Still grappling with the dilemma of disclosure, they did not place their child in group daycare or school settings.

Telling the HIV-positive child or their siblings was an additional, but major, dimension of the mothers' experience of disclosing the HIV/AIDS diagnosis. All mothers felt that they should tell the children. However, they believed timing of such disclosure to be related to the child's ability to understand the meaning of being chronically ill as well as the need for discretion in telling others or secrecy, if needed.

HIV-positive mothers developed strategies to help her and her child manage the physical and emotional aspects of having HIV. She maintained their health, focused on facing each challenge one day at a time, and learned about HIV so she could give the best care possible. She sought other mothers like herself, HIV-positive with an HIV-positive child, but they are not a visible group. Like herself, they were often part of other HIV women's groups, but felt it was not the same as sharing with someone who lives her life as a mother with an HIV-positive child. Like many chronically-ill persons, she tried to maintain normalcy in their lives to distance themselves from stigmatization and rejection. She tried to instill a sense of the future in her child, so that when the day of disclosure to her child came, the experience could happen within a context of living with, not dying of, HIV infection.

Implications for Research

Previously published research provides a cursory description and identification of issues facing the pediatric HIV family. The findings from the present study describe the reality of the experience as told by the mothers who live it. It supports some of the previous research findings as well as uncovers additional related concepts. However, research is needed to increase the understanding of the internal (characteristics of the individual) and the external (sociocultural factors) influences on the quality of life for the HIV-positive mother with an HIV-positive child. Further study is needed to examine the influence of sociocultural factors on the mother and child's health outcomes, including mental health and quality of life, over time. For example, stigma may be one of a number of factors that influence health outcomes. Those factors, the conditions under which they occur, and their impact must still be identified.

Further, several methodological issues used in previous studies threaten the interpretation of their data. Generally, quantitative studies did not report whether statistical power had been attempted or achieved for their selected sample size and so, reports of difference between variables or groups must be interpreted with caution. Data analysis must consider variables that include, but are not limited to, drug use, poverty, general health status, nutrition, violence or abuse, and family functioning. Such analysis requires multivariate techniques to determine relationships between, and effects of, such variables.

In addition, research designs must expand from their primarily cross-sectional descriptions. As the clinical spectrum of pediatric AIDS expands to include chronic conditions, longitudinal designs must be included to determine psychosocial and behavioral changes over time for mothers, children, and their families. Due to the limitations in recruiting subjects with HIV/AIDS (primarily related to issues of confidentiality), sampling continues to rely on convenient sampling methods. Although some of the reviewed studies, as well as the current study, have included heterosexual families, the numbers remain small. Consequently, published findings have been based on predominantly Caucasian, gay male samples. Fortunately, much is known about the characteristics and needs of HIV/AIDS adults and caregivers but, unfortunately, much continues to be presumed about those of the HIV-positive mother-child family.

Implications for Nursing Practice

The increased trend toward nursing responsibility for case management requires the individualization of any illness experience in order to maximize resource utilization and thus maximize health outcomes. To do so, however, requires a base of knowledge not yet available on the mother-child HIV-infection phenomenon. Consequently, it is important that nurses who provide care maintain the perspective that the family disruption caused by HIV may not be readily apparent. For example, while treatment and care issues are apparent concerns, transportation, housing, school placement, poverty, even legal status can affect any health care interventions. The disruption extends to the social context of the family as well. While mothers are likely to be the primary caregivers for infected family members, they may neglect their own health. It is likely that well siblings may be providing that care as well. If the HIV infection is secret, resources are further limited.

The implications for nursing highlighted by this study crosses management as well as clinical practice. For the nurse providing case management, all family members must be considered and their role within the family established. Mothers cannot be presumed to have resolved future custody or care issues for their child(ren). Primary decision makers must be identified and the plan of care tailored to the family. Priorities for the family must be identified and addressed. Any system of case management must provide the foundation for coordinating services to the HIV-positive mother-child family.

The study also emphasizes the need for practitioners to recognize their biases regarding mothers who have infected their child. Despite the ongoing public educational efforts regarding HIV disease, HIV-infected individuals continue to report stigmatization and rejection from close friends, relatives, and health care providers, reinforcing their fear of negative consequences from exposure of their disease. Identified problems and potential resolutions should be approached without blaming or imposing judgment, especially when patient decisions conflict with the practitioner's belief of appropriate care or treatment.

This study reveals that the extent of the burden of HIV disease may not appear as harsh or overwhelming when they are likely to be both. Nursing provides the opportunity to help clients both physiologically and psychosocially so that the HIV-positive mother with an HIV-positive child may focus on her experience as living with HIV disease, not dying of it.

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Appendix A

HIV-Positive Women: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Suffet & Lifshitz (1991)	Exploratory-Descriptive To identify women addicts' response to risk of AIDS	N = 30 Mothers or currently pregnant History of injection drug use Mean age: 30.6 yrs	Instrumentation • Semi-structured, open-ended interviews Analysis • Content analysis of interviews	Fear: AIDS Risk Assessment • friends/family deaths from AIDS • high-risk for self & children AIDS Risk Reduction Behaviors • stop sharing/using needles • did not stop using drugs • practice protective sexual behaviors Antibody Testing Avoided due to: • fear of having AIDS • fear of knowing they infected children
Hutchinson & Kurth (1991)	Exploratory-Descriptive To identify factors influencing decision-making of HIV+ women to continue or terminate pregnancy	N = 11 Diagnosed during pregnancy at <24 weeks gestation	Instrumentation • Semi-structured, open-ended interviews Analysis • Reported only as "standard qualitative methodologies"	Influencing Factors to Continue Pregnancy • personal morality • desire for child • religious faith • advanced state of pregnancy • having a prior child serorevert Influencing Factors to Terminate Pregnancy • desire to avoid stigma for child • counseling advice • fear of labor/delivery • fear of inability to care for child • no adoption options • prior experience waiting for child to serorevert

Appendix A (continued)

HIV-Positive Women: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Frank, Blundo, & Brabant (1995)	Descriptive Survey To identify financial, physical & emotional state of HIV+ women and relationship to identified psychosocial considerations	N = 32 Age range: 16 - 65 yrs <30 yrs = 53% >30 yrs = 47% African American = 19 White = 12 Native American = 1	Instrumentation 3-part Questionnaire • General needs assessment (yes/no) • Immediacy & degree of need (Likert) • 6 open-ended statements Analysis • Descriptive statistics • T-tests (difference between groups) • Chi-square (significance of relationship of variables)	Needs Assessment • Most: financial, health insurance & medicines • Least: childcare, help with ADLs, substance abuse treatment • Minority women less likely to perceive need for support groups Immediacy & Degree of Need • Disease progression does not necessarily result in ↑ financial or emotional need • Women w/children not likely to have greater financial need than those without • T-cell>200 = ↑ financial aid, insurance, spiritual support, legal assistance • T-cell>500=need for support groups Feelings • Children important factor in emotions • HIV/AIDS more likely source of anger for women >30 yrs old & for whites • HIV/AIDS greatest source of feeling helpless for non-whites & women with children

Appendix A (continued)

HIV-Positive Women: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Ickovics, Forsyth, Ethier, Harris, & Rodin (1996)	Exploratory-Descriptive To identify factors that influence delayed entry into health care for HIV+ women	N = 48 HIV+ women Sequential sampling from 2 hospital AIDS clinics Mean age = 31.2 yrs Ethnicity: • African American or Latina - 60% Timing of Diagnosis: • Prenatal - ⅓ • Self-referred - ⅔	<u>Instrumentation</u> • Structured interviews • Medical chart reviews <u>Analysis</u> • Descriptive statistics	<u>Delayed Entry Following HIV Diagnosis</u> • delayed entry into care >3 mos. = 48% • mean delay = 17.6 mos (range 4 - 34 mos) • no significant differences by sociodemographic and health variables between women who delayed and those who did not • prenatal diagnosis 4x more likely to delay entry to care • women of low SES and of color 2x more likely to delay • no difference in delayed entry due to infection by injection drug or heterosexual transmission <u>On Entry to Health Care</u> • symptomatic for HIV = 64.5% • CD4 cells/mm^3 <500 = 72.5 %

Appendix A (continued)

HIV-Positive Women: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Moneyham, Seals, Demi, Sowell, Cohen & Guillory (1996)	Exploratory-Descriptive To examine the disclosure experiences of HIV+ women	N = 19 HIV+ women With children = 18 Single = 15 Married = 4 <u>Focus Groups</u> (n = 4) All African American = 2 All Caucasian = 1 Mixed = 1	<u>Instrumentation</u> • Focus groups • Semi-structured, open-ended interviews <u>Analysis</u> • Content analysis	Themes of concerns regarding disclosure • discrimination • confidentiality • context of disclosure
Moneyham, Seals, Demi, Sowell, Cohen & Guillory (1996)	Exploratory-Descriptive To examine the perceptions of stigma in HIV+ women	N = 19 HIV+ women Same database as 1996 research (above)	<u>Instrumentation</u> • Focus groups • Semi-structured, open-ended interviews <u>Analysis</u> • Content analysis	Four themes of perceived stigma • distancing • overgeneralizing stereotypes • social discomfort • pity

Appendix B - Part I

HIV/AIDS Families- Non-pediatric: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Trice (1988)	Descriptive Survey To compare caregiver mothers with noncaregiver mothers for PTSD symptoms	N=43 mothers with sons who died from AIDS Caregivers =19 Mean age: 59 Noncaregivers = 24 Mean age: 51	Instrumentation Interviews by phone (33) or face-to-face (10) • PTSD symptoms • extent of care & attitudes toward care Analysis • Descriptive statistics	Caregivers experienced more PTSD symptoms, except drug & alcohol use, than non-caregiver group
Brown & Powell-Cope (1991)	Exploratory-Descriptive To explore & describe experience of family members caring for PWAs at home	N=53 Ages: 22-65 Mean: 36 Gay = 68% Male = 64% White = 92%	Instrumentation • Open-ended interviews Analysis • Grounded Theory • Descriptive statistics	Theory of AIDS Family Caregiving Problem: Uncertainty Category: Transitions through Uncertainty • Subcategories: 1. Managing/Being Managed by Illness 2. Living with Loss & Dying 3. Renegotiating the Relationship 4. Going Public 5. Containing the Spread of HIV
Brown & Powell-Cope (1993)	Exploratory-Descriptive To describe loss & dying among AIDS family caregivers	N=53 (same database as 1991 study - see above)	Instrumentation • Open-ended interviews Analysis • Grounded Theory • Descriptive statistics	• Subcategory: Living with Loss & Dying 1. facing loss (anticipatory grief, sadness, anger, fear) 2. transformed time (one day at a time, living in the present, actualizing future dreams)

Appendix B - Part II

HIV/AIDS Families - Pediatric: Review of Selected Research

Note: When the study reported is a preliminary finding of a larger study, both preliminary and major study information is provided.

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Reidy, Taggart, & Asselin (1991)	Descriptive Survey To describe caregiver perceptions of their psychosocial needs	N=30 caregivers from 21 families Mothers=13 Fathers=5 Other Family=12	Instrumentation • Instrument developed to measure categories of 5 needs by: 1) most important to caregiver 2) most satisfied by health care team • Open-ended interview Analysis ANOVA (differences in importance & satisfaction) TUKEY (pairwise comparison)	Important Needs: • to learn about HIV: prevention & protection; honest & current info • respect & support from health care team • emotional, functional, & financial assistance Most Satisfied by Health Care Team: • current HIV info; honest & current info on child's illness • respect & support from health care team
Clemo (1992)	Descriptive Survey To determine if prejudicial attitudes re: AIDS affect nat'l policymaking for pediatric HIV issues	N=31 lobbyists for children's interest groups	Instrumentation Mailed questionnaire (response rate = 78%) Analysis • Descriptive statistics	• Lobbyist influence on AIDS issues <10% compared to other efforts (>76%) • Main barrier to efficient response on AIDS issues identified as stigma attached to pediatrics due to AIDS association with high-risk populations

Appendix B - Part II (continued)

HIV/AIDS Families - Pediatric: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Melvin & Sherr (1993)	Preliminary Findings			
	Exploratory-Descriptive To describe the care issues of HIV+ children & their families	N = 18 families mothers = 14 fathers = 8 (some families had two parents) Geographic location: London	<u>Instrumentation</u> Not reported <u>Analysis</u> Not reported	Preliminary findings from 3 case studies. <u>Care Issues</u>: • conflicting & competing needs of adult & child (parent may neglect own care for child) • emotional support (i.e. guilt, grief/loss, secrecy, anxiety, panic, moodiness) • developmentally appropriate care facilities • support developmental growth & progress; disrupted parenting, separations • consideration of culture, language, & religion as they affect attitudes, expectations, experiences of childcare practices, and developmental/psychological measurements
	Major Study			
	Major study reported only as: "longitudinal psychological study of HIV+ children at a London hospital"	Not reported.	Not reported.	Ongoing study.

Appendix B - Part II (continued)

HIV/AIDS Families - Pediatric: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Sherwen, Boland, & Gilchrist (1993)	Preliminary Findings			
	Descriptive Survey To compare psychological family structure variables in 3 HIV family units: • biological • extended • foster	N= 56 female caretakers of HIV+ child <7 yrs old biological = 26 extended = 21 foster = 9 Age range = 19-64	<u>Instrumentation</u> • FILE (Family Inventory of Life Events & Changes) • FACES III (Family Adaptability & Cohesion Evaluation Scales III) • F-COPES (Family Crisis Oriented Personal Evaluation Scales) • FCVS (Family Child Vulnerability Scale) <u>Analysis</u> • Descriptive statistics • Simple parametric (t tests & ANOVA)	No statistical significant differences between VTHIV family units. <u>Emerging patterns:</u> • extended families report more stressful life events& changes; least adaptive &cohesive • extended & foster families use different coping strategies • denial of child's health vulnerability • sources of stressful life events: foster = job/career issues extended = general family conflicts • coping strategies: foster: friends support, NOT families biological: family support, NOT friends
	Major Study			
	Descriptive Survey To compare psychological variables in 3 family units (above) for: • VTHIV • cancer • sickle cell disease	Ongoing recruitment	<u>Instrumentation</u> • same as above <u>Analysis</u> • same as above	Ongoing study.

Appendix B - Part II (continued)

HIV/AIDS Families - Pediatric: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Barrett & Victor (1994)	Exploratory-Descriptive To describe parents' feelings re: • about HIV • experience with health care services	N = 10 parents of VTHIV children Child age range: 5 mo-11 yr	Instrumentation • Semi-structured interview Analysis • Not reported	Experiences with Health Care Services • rejection from personal MD after dx • refusal to care by some health services • difficulty in managing multiple appts • need separate child & adult clinics Feelings about HIV • positive; also anxiety & uncertainty • anxiety of mother's illness or concurrent hospitalization of parent & child • wish to die quickly; suicide thoughts
Black, Nair, & Harrington (1994)	(see next page)			

Appendix B - Part II (continued)

HIV/AIDS Families - Pediatric: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Black, Nair, & Harrington (1994)	Experimental, longitudinal comparison To compare parenting and early childhood development of children to HIV+ and HIV- women following home intervention Intervention: parenting support using Carolina Preschool Curriculum & Hawaii Early Learning Program	N = 50 Intervention Group: HIV+ moms = 14 HIV- moms = 17 Control Group: HIV+ moms = 10 HIV- moms = 19 Child's HIV status: HIV+ = 6 total (Not specified by group of mothers)	<u>Instrumentation</u> • Child Abuse Potential Inventory • Family Support Scales • Family Adaptability & Cohesion Evaluation Scale (FACES III) • Parenting Stress Index • Bayley Scales of Infant Dev. • Parent Child Early Relational Assessment (modified) • HOME Scales Measurements @ 3, 6, 9, 12, 18, & 30 months <u>Analysis</u> • Multivariate Analyses of Covariance (MANCOVA): baseline differences • Repeated Measures MANCOVA: change over time • MANCOVA: differences in variables as (a) Function of HIV status and intervention/control and (b) HOME scores and parent-child interaction scores	No effects by HIV status or intervention for baseline measures of: child abuse potential, family support, family functioning, parent or child stress. <u>6 months</u>: • ↑scores in mental development for child w/HIV+ mom>w/HIV-mom • significant differences in motor development <u>9 months</u>: • no significant difference in parent-infant interaction by HIV status or intervention <u>18 months</u>: • HIV+ moms w/intervention with more normative scores for child abuse potential than HIV- moms • child-related stress > for HIV- moms than HIV+ moms <u>30 months</u>: • all moms w/intervention more likely to have child-centered home & score higher for maternal emotional & verbal responsiveness

Appendix B - Part II (continued)

HIV/AIDS Families - Pediatric: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Hardy, Armstrong, Routh, Albrecht, & Davis (1994)	Descriptive Survey To compare coping patterns among three groups of children & their parents: • symptomatic VTHIV • cancer (<40% mortality rate) • control group: healthy children	N = 60 mothers = 58 fathers = 2 Mean age (yrs): HIV+ = 5.0 Cancer = 5.45 Control = 5.3 Child aware of dx: HIV+ = 5 Cancer = 19	<u>Instrumentation</u> • CSI (Coping Strategies Inventory) adapted from 72 to 32 items <u>Analysis</u> • Descriptive analysis • TUKEY (pairwise comparison) • Multiple regression	<u>Coping Strategies</u> (significant findings) • wishful thinking: used by more HIV+ than cancer moms; HIV+ & cancer moms used more than natural moms covariate = ethnicity • self-criticism: practiced by more control than cancer moms covariate = SES & child's age • no differences in parent report of child coping across groups <u>Communication</u> • disclosure of illness to child: natural moms more likely to discuss illness with child than foster mothers

Appendix B - Part II (continued)

HIV/AIDS Families - Pediatric: Review of Selected Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Mellins & Ehrhardt (1994)	Exploratory-Descriptive To describe families of HIV+ children: • stressful experiences • coping strategies • psychosocial needs	N = 52 participants from 25 families • Caregivers = 31 • HIV+ child = 14 (age 4-14 yrs) • Siblings = 6 (age 11-16 yrs) Family structure: single parents = ⅓ extended = ⅓ adoptive/foster = ⅓	Instrumentation • Open-ended interview Analysis • Descriptive statistics • Content analysis	Stressful Experiences HIV+ parents: • illness management • secrecy & disclosure • multiple family infections & deaths HIV+ children: • sibling/parent death from AIDS • family conflict; school problems Uninfected siblings: • secrecy & burden of caregiving for HIV+ siblings & HIV+ parents Coping HIV+ parents & caregivers: • emotion-focused: religion most imp. HIV+ children: • family, friends, professional support • wishful thinking for normalcy Non-infected siblings: • relies on self; few resources for support Psychosocial Needs Parents & Caregivers: • respite care most important • professional help to communicate with MDs & social agencies; deal with child behavior problems & disclosure issues • need family help w/stress & childcare

Appendix C

HIV-Mother - HIV-Positive Child: Review of Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Andrews, Williams, & Neil (1993)	Preliminary Findings			
	Exploratory-Descriptive To describe the mother-child relationship in HIV-1 family	N = 72 Mothers of HIV+ children Mean age: 30.3 yrs Drug/ETOH use: current = 37% former = 38% methadone = 10% never used = 15%	<u>Instrumentation</u> • Open-ended interview (x2) mother-child relationship <u>Analysis</u> • Descriptive statistics • Content analysis of interviews	<u>Relationship Perceived as Supportive</u> • decreases isolation; increases attachment to world • mom forced to stay positive about life • increases self esteem • reason to cease high-risk behaviors <u>Relationship Perceived as Burdensome</u> • anxiety re: placing surviving children • fear of child's illness course, long hospitalizations, and death • decreased maternal privacy • children's angry/hostile reactions to mother re: her being infected
	Major Study			
	Same as above	Target = 125	<u>Instrumentation</u> • Medical records review • Norbeck Social Support Questionnaire • Addiction Severity Instrument <u>Analysis</u> • Not reported	Ongoing study.

Appendix C (continued)

HIV-Mother - HIV-Positive Child: Review of Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Butz, Hutton, Joyner, Vogelhut, Greenberg-Friedman, Schreibeis, & Anderson (1993)	Descriptive Survey To describe maternal social & health characteristics assoc'd with: • infant utilization & adherence to health care • maternal utilization & adherence to health care	N = 90 HIV+ mothers Ethnicity: African American = 93.3% White = 6.7% Incarceration: current = 2.2% past hx = 12.2% HIV Risk Factor: drug use = 65.6% sex contact = 27.8% both = 5.5% Repeat Pregnancy: Yes = 19%	<u>Instrumentation</u> • Interview • Medical records (infant immunization record) • Clinic records (HIV clinic attendance by mother) <u>Analysis</u> • Descriptive statistics • Chi-square test of association (relationship of maternal characteristics to mom seeking care)	<u>Maternal Adherence</u> = 46% (attending HIV clinic during pregnancy or 12 months postpartum) • associated with mother seeking health care for herself: 1. HIV+ status of infant (strongest association) 2. no history of incarceration 3. HIV risk factor is sexual contact • not associated with seeking health care: 1. repeat pregnancy 2. education 3. age 4. marital status <u>Infant Utilization and Adherence to Health Care</u> • infant adherence = 73% (having adequate immunization status by 9 months of age) • may be due to intensive follow-up by pediatric staff

Appendix C (continued)

HIV-Mother - HIV-Positive Child: Review of Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Cohen , Nehring, Malm, et al. (1995)	Preliminary Findings			
	Exploratory-Descriptive To describe issues experienced by four biologic and four foster families of VTHIV children	N = 10 parents of VTHIV children <3 yrs old (Midwest US) mothers = 8 fathers = 2	<u>Instrumentation</u> • Interview guide <u>Analysis</u> • Content analysis	<u>Major Themes: Family Issues</u> Biologic families: • all biologic moms expressed guilt • future uncertain; live day-to-day • fear of preceding child in death so no one would be available to care for dying child Foster families: • natural children of foster mother fear disease transmission • eventually accepted foster child & were an asset in child's care
	Major Study			
	Descriptive Survey To compare family environments and supports of: • VTHIV families • control families	Not reported	<u>Instrumentation</u> • Quantitative measures of family environment & supports (not specified)	Ongoing study.

Appendix C (continued)

HIV-Mother - HIV-Positive Child: Review of Research

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Rose & Clark-Alexander (1996)	Descriptive Survey To measure the coping behaviors of mothers with HIV/AIDS	N = 52 Age range = 18-39 yrs Mean since dx = 2.3 yrs African American = 65% White = 23% Hispanic = 12% Single = 75% Married = 25%	<u>Instrumentation</u> • Jalowiec Coping Scale - confrontive - passive - emotive <u>Analysis</u> • Descriptive statistics • Analysis of Variance (ANOVA) (differences between ethnic groups) • Independent t-tests (differences between AIDS & HIV+ women)	• confrontive coping most used, although all three methods used by all women • no difference by ethnic groups except African American women use more passive coping than white women • HIV/AIDS mothers choose confrontive more often than emotive coping style • drug and alcohol use increases passive & emotive coping • women score higher in meeting child's needs than their own

Appendix D

Personal Profile of Respondents

Mother	Age	Ethnicity[1]	Total Children in Home	Partner Status Before Dx[2]	Partner Status After Dx	Income[3]	Education (Years or <HS)	Religion[4]	Residence[5]
45F6.6	45	AA	1	Married	Divorced	SSI	14	none	single fam unit
35M3.6	35	C	1	LWP	No change	SSI	16	none	Drug recovery
42F0.5	42	AA	1	LWP	Separated	SSI	14	none	single fam unit
31F1.4	31	AA	1	Single	No change	SSI	15	Baptist	single fam unit
30F8.0	30	AA	2	Married	Separated	SSI	13	none	shares w/grandmother
45M4.0	45	AA	3	Married	Separated	SSI/AFDC	14	Baptist	single fam unit
28F0.5	28	HISP	1	Single	No change	None	<HS	Cath	Dept Of Corrections
37M4.6	37	C	0	LWP	Separated	F-T Job	14	Jewish	single fam unit
22F5.0	22	HISP	0	Married	Married	SSI	<HS	Cath	single fam unit
36M3.2	36	AA	0	Single	No change	Gen Assist	< HS	Baptist	single fam unit

Appendix D (continued)

Personal Profile of Respondents

Note: Key to Mothers' codes and other abbreviations provided on last page of appendix.

Mother	Age	Ethnicity	Total Children in Home	Partner Status Before Dx	Partner Status After Dx	Income	Education (Years)	Religion	Residence
34M4.10	34	AA	1	Single	No change	AFDC	<HS	none	AIDS housing
26M4.3	26	Hisp	1	LWP	Separated	Gen Assist	HS	Cath	single fam unit
35F3.11	35	AA	3	LWP	Separated	SSI/AFDC	14	Baptist	single fam unit
32M4.9	32	AA	1	Single	No change	AFDC	HS	no belief	AIDS housing
43F4.2	43	Ca	1	Single	No change	AFDC	HS	none	AIDS housing
31F3.4	31	Ca	1	LWP	Separated	SSI/AFDC	HS	none	single fam unit
36M1.2	36	AA	3	Single	No change	SSI/AFDC	13	Baptist	single fam unit
25M1.8	25	AA	1	Single	No change	AFDC	<HS	ND	Drug recovery
41F1.1	41	AA	1	Single	No change	SSI/AFDC	HS	ND	single fam unit
33M2.2	33	AA	1	Single	No change	SSIC	HS	none	single fam unit

Appendix D (continued)

Key to Codes and Abbreviations

Mother's Code= Mother's Age, Child's Gender, Child's Age (years.months)

example: 45 year old mother with HIV+ daughter 18 month old
↕ ↕ ↕
45 F 1.6 (years.months)
45F1.6

[1] AA = African American; Hisp = Mexican American, Honduran; Ca = Caucasian

[2] LWP = single, living with partner

[3] SSI = Supplemental Security Insurance; AFDC = Aid to Families with Dependent Children

[4] ND = nondenominational religious group; None = no organized religious group

[5] Housing indicated as for AIDS or drug recovery are subsidized for those populations.

Appendix E

Mother's Report of Health Profiles for Self & Child

Mother	General Health	Treatment	Child (Sex/Age)	General Health	Treatment
45F6.6	Very good • 6 months pregnant • T-cells ~700	AZT per prenatal protocol acupuncture herbs	F/6 yr 6 mo	Poor • chronic infections • shingles	AZT
35M3.6	Very good • asymptomatic	AZT acupuncture herbs meditation	M/3yr 6 mo	Excellent • chronic ear infections	AZT
42F0.5	Very good • asymptomatic	herbs	F/5 months	Fair • chronic ear infections & URI[1]	Antibiotics as needed
31F1.4	Very good • asymptomatic	Pentamidine	F/16 months	Excellent	None
30F8.0	Very poor • renal failure • chronic diarrhea • pancreatitis • neuropathies • weight loss >100 lbs in past 6 months	Multiple drugs	F/8 yr	Good • T-cells<500 in past year	AZT

Appendix E (continued)

Mother's Report of Health Profiles for Self & Child

Mother	General Health	Treatment	Child (Sex/Age)	General Health	Treatment
45M4.0	Good • asymptomatic	None	M/4 yr	Poor • chronic ear infection • T-cell <200 • small for age	AZT
28F0.5	Very good • asymptomatic	None	F/5 months	Very good • asymptomatic	AZT
37M4.6	Very good • asymptomatic	None	M/4 yr 6 mo	Good • pneumonia x4 past 12 months • hospitalized x2 • viral load >100,000	Septra
22F5.0	Very good • T-cell ~1000 • viral load undetectable	None	F/5 yr	Very good • T-cell ~1600	None
36M3.2	Very good • asymptomatic	None	M/3 yr 2mo	Very good • asymptomatic	None

Appendix E (continued)

Mother's Report of Health Profiles for Self & Child

Mother	General Health	Treatment	Child (Sex/Age)	General Health	Treatment
34M4.10	Very good • asymptomatic • T-cell ~1000 • viral load undetectable	None	M/4 yr 10 mo	Very good • T-cell ~470 • viral load - undetectable • Attention Deficit Disorder	Clinical trial
26M4.3	Very good • asymptomatic	None	M/4 yr 3 mo	Very good • asymptomatic	None
35F3.11	Very good • asymptomatic	AZT herbs	F/3 yr 11 mo	Severely ill • currently in pediatric hospice home • CMV infection • blind • severe developmental delays • small for age	Multiple drugs
32M4.9	Very good • yeast infections	None	M/4 yr 9 mo	Good • chronic URI	None

Appendix E (continued)

Mother's Report of Health Profiles for Self & Child

Mother	General Health	Treatment	Child (Sex/Age)	General Health	Treatment
43F4.2	Fair • chronic diarrhea	AZT	F/4 yr 2 mo	Poor • chronic ear infections • chronic URI	None
31F3.4	Good • asymptomatic	herbs	F/3 yr 4 mo	Poor • intermittent diarrhea • chronic URI	Symptom management
36M1.2	Very good • asymptomatic	None	M/1 yr 2 mo	Very good • asymptomatic	AZT
25M1.8	Very good • asymptomatic	None	M/1 yr 8 mo	Good • chronic ear infections	AZT
41F1.1	Very good • asymptomatic	AZT	F/1 yr 1 mo	Very good • asymptomatic	None
33M2.2	Very good • asymptomatic	None	M/2 yr 2 mo	Very good • asymptomatic	None

Key:
[1] URI = upper respiratory infection