Family and Self-Care Management of HIV infected Women and Their HIV infected Children

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Abstract
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Carol Ann Vincent

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Conclusions: While further testing of the Vincent Model is needed in larger populations, the results underscore the importance of assessing both psychosocial and clinical measures in mothers and children. Finally, advocacy for the appropriate care of individuals infected with HIV as well as for the special needs of these family members is crucial.

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FAMILY AND SELF-CARE MANAGEMENT OF HIV INFECTED WOMEN AND THEIR
HIV INFECTED CHILDREN

Carol Ann Vincent

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Nursing

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in

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Degree of Doctor of Philosophy

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Dedication

To the mothers and children who participated in this study. I will be forever grateful for your gift of time and your willingness to share your experiences of living with chronic illness.

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One of the most important things in life is family. Through the years, I have learned that without the support of family, life is more difficult to navigate. I have also learned that family can be defined however one wishes to define it. Throughout this educational journey, I have relied on many people. Each one of these people I consider my family. These are the people who have always been there when I had questions, tears, doubts, worries and successes. My family has been there every step of the way to support me.

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to keep going in this process. Dr. Douglas has been a wonderful mentor for twenty years. Thank you for believing in me and always supporting me in my scientific endeavors. Your enthusiasm for science makes me want to come to work every day. Dr. Richard Rutstein has been my clinical mentor since 1992. Rick, you continue to teach me every day. Your enthusiasm for pediatric health care is one of the reasons I love what I do. I could not have worked and completed this process without the unending support of these three mentors and my dissertation committee.

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ABSTRACT

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Janet A. Deatrick

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CHAPTER 1

Introduction and Background

Chronic conditions such as cancer, diabetes, cardiovascular disease, and human immunodeficiency virus (HIV) disease are leading causes of death in the world. The number of people living with chronic conditions is increasing (CDC, 2012; RWJF, 2006). Nearly half of the United States (U.S.) population, about 145 million persons, are living with at least one chronic condition. Chronic conditions and their complications account for 70% of all deaths annually in the U.S. Among the 7 out of 10 individuals who die each year of chronic conditions, approximately 40% are between the ages of 25 to 44 years, many who are women of childbearing age (CDC 2012; Kung, Hoyert, Xu & Murphy, 2008).

A substantial number of children are also affected by chronic conditions. Over the past several decades, childhood chronicity has been redefined to include physical, developmental, emotional and behavioral conditions. With this redefinition, the proportion of children identified as chronically ill and disabled was no longer 5-8% but had increased to 16-18% classified as having special needs due to chronic conditions. This shifting definition speaks to the necessary response to the changing epidemiologic realities of childhood chronic conditions (Bethell, Read, Blumberg & Newacheck, 2008; Halfon & Newacheck, 2010; McPherson, Arango, Fox, et al 1998). The majority of these children (85%) will live into adulthood (Reid, Irvine, McCrindle, Sananes, Ritvo, Siu & Webb, 2004). “Increasing rates of childhood chronic conditions portend major increases in long-term pulmonary, cardiovascular and mental health burdens among adults, accompanied by increasing expenditures for health care and disability programs, and
decreased work force participation and quality of life” (Perrin, Bloom & Gortmaker, 2007, p. 2756) making this a national health priority in the U.S.

Because of advances in medical science, conditions that once shortened the lifespan have instead become chronic medical issues allowing one to function in daily life and roles, including parenting. Persons living with chronic conditions can be affected by the prolonged course of illness and disability, which affects quality of life and the way individuals manage their self-care. Also, families are challenged to manage the daily demands of caring for an ill family member (i.e. family management). The context in which family subsystems adapt and manage may be influenced by the type and duration of the condition, as well as condition related demands (Lewis, Woods, Hough & Bensley, 1989).

Some families have more than one member with the same chronic condition. Of particular concern are conditions that are inherited, congenitally, or perinatally acquired. Conditions such as cystic fibrosis, sickle cell anemia and HIV disease are examples of relatively common conditions in which the mother and the child may be affected by the same condition.

HIV, the focus of the current study, is a striking example of the complexity of chronic conditions, as this condition not only impacts the infected mother and child, but also affects the other family members. As such, the mother’s quality of life (QOL), mood (depression), capacity for self-care, and HIV disease severity (CD4 count and HIV viral load), as well as family management of the child’s illness may all play some part in maternal and child HIV outcomes. Thus, both family and self-care management for mothers and their children infected with HIV will be explored. In order to identify the significance of these phenomena, the following will be described based on the current literature: a.) the context of chronic illness; b.) the effects of chronic illness on the
individual and family; c.) HIV self-care demands; d.) the mother and child- sociocultural aspects of HIV; e.) families’ experiences with HIV and f.) family management of the child’s illness.

The Context of Chronic Illness

Chronic diseases are roughly defined as health conditions that have a predicted or actual course that lasts longer than 12 months (Perrin, et al., 2007). Diagnosis with a chronic disease does not adequately predict how the individual and family will experience or manage the disease in the context of the individual or the individual’s family. In contrast, the term illness refers to the human experience of symptoms of suffering rather than the disease itself (Aronowitz, 1998; Kleinman, 1988). Chronic illness is defined as a permanently altered health state, caused by a non-reversible pathological condition, which leaves residual disability that cannot be corrected by a simple surgical procedure or cured by a course of medical therapy. The course of chronic illness can be progressive, constant or episodic (Miller, 1992; Newby, 1996; Shaw & Halliday, 1992). The concept of chronic illness captures the difference between the lived experiences of the individual versus the system of knowledge developed by the biomedical world (Aronowitz, 1998). In other words, illness is a social construct with meaning beyond the biological facts of disease (Sontag, 1983, 1990). How individuals and their families live with the long-term effects of chronic disease, the demands of the illness, and how they manage the day to day demands of the illness influences the effectiveness of therapy and outcomes in the functional, developmental, quality of life, biologic and psychosocial domains (Deatrick, 1998; Grey & Sullivan Bolyai, 1999; Halfon & Newacheck, 2010; Sawyer & Aroni, 2005). Effective therapy is as important in affecting long-term outcomes as how the individual and family manage those therapies (Simoni, Pearson,
Thus, much of the chronic illness literature focuses on quality of life, psychosocial issues affecting quality of life such as depression, self-care and family management of illness. Because of the nuanced differences between ideas of illness and disease, the more neutral term, chronic condition, will also be used.

The effect of chronic illness on the individual and the family

Chronic illness, a construct which was defined to understand the multidimensional effects of disease, includes events and experiences that individuals and families attribute to the illness that may tax the family’s social and personal resources and well-being (Woods, Haberman & Packard, 1993; Woods, Yates & Primomo, 1989). Demands are generated by the direct and indirect physical and psychological effects of the disease and its treatments. Also, demands may include transactions with health services, extended family, school and work environments. Further, there may be pressure to change family roles and decision making in order to manage the disease. Illness demands are the perceptions of individuals and may vary during the course of the illness (Knafl & Gilliss, 2002; Swendeman, Ingram & Rotheram-Borus, 2009; Woods, Yates & Primomo, 1989).

The demands of chronic illness have a profound effect on the individual, but also places immense responsibility upon the family (Bor, Miller & Goldman, 1993; Miller, 1992; Newby, 1996; Shaw & Halliday, 1992). These demands imposed on the family are not only managed by the ill individual, but also by formal caregivers (professional and lay) and informal caregivers (family members). The resultant intrafamily processes are an essential starting point in understanding family management of chronic illness. A fruitful area of research is in identifying and studying physical, psychological, and social variables, which comprise these intrafamily demands in HIV disease (Swendeman,
Ingram & Rotheram-Borus, 2009), especially in families coping with multiple infected members.

While HIV-related science is relatively young, evidence exists regarding the connections among family member perceptions of family management or family processes underlying illness management and treatment outcomes for other conditions (Knafl & Deatrick, 2003, Lewis, Woods, Hough, Bensley, 1989). Thus, family management is a potential key to understanding how to design efficacious interventions for individuals and families affected by HIV in the future. The first step is to identify and describe those issues that may be important in understanding family management in this population. That is, determining the relationship of chronic illness demands (including self-care [individual processes underlying illness management] and family management [family processes underlying illness management] to long term outcomes (HIV viral control and immune stability) will be the first step in the investigators’ program of research (Knafl, Deatrick & Gallo, 2008; Nelson, Deatrick, Knafl, Alderfer & Ogle, 2006). The long-term goal in the investigator’s program of research is to improve the quality of life for these mothers and their children.

**HIV Self-Care Demands**

In the U.S., HIV is becoming a chronic manageable disease due to better pharmacologic treatments and increased services (CDC, 2012a; Cohen, 1994; El-Sadr, Mayer and Hodder, 2010; Ledlie, 2001; Nelms, 2005; Pequegnat & Bray, 1997). As such, the increased life expectancy and improved quality of life in persons with HIV has posed new challenges for families living with the disease. However, there are multiple physiologic, psychological, and emotional consequences for persons infected with or affected by HIV (Buchacz, Rangel, Blacher & Brooks, 2009; Leserman, 2008; Lewis,
HIV disease management may add the following burdens: daily medication; visits to a health care provider at least every three months; missed time from school, work or social events; co-morbid illnesses; disease progression; and medication and HIV related side effects. Optimal management of HIV disease is achieved through viral suppression, which requires greater than 95% anti-retroviral therapy adherence to maintain viral suppression (Enriquez, Lackey, O’Conner & McKinsey, 2004). Viral suppression or undetectable viral load is defined as a confirmed HIV RNA (HIV viral load) level below the limit of laboratory assay detection (usually < 48 copies/ml) (DHHS 2008; DHHS, 2010). Adherence to medications is important in managing chronic diseases, including HIV; poor adherence may lead to drug resistance and treatment failure (Enriquez, et al., 2004). Adequate self-care and family management are therefore crucial to addressing the demands of the disease and suppressing it.

The Mother and Child with HIV

Despite advances in prevention that include early detection and treatment, behavior change, blood product screening, and antiretroviral regimens which reduce HIV transmission, new HIV infections are still occurring in the U.S. In addition, more than 1.1 million Americans are estimated to be infected with HIV, including an estimated 20% who are unaware of their infection status (CDC, 2012b). Therefore, HIV infection is still a significant public health concern.

Women currently account for 27% of new HIV infections in the U.S., largely through heterosexual contact. The majority of children (18 years and younger) with HIV acquired the disease through perinatal transmission. Children living in high resource countries with perinatally acquired HIV now have a life expectancy that extends into adolescence and beyond. Pediatric HIV has changed from a disease of near certain mortality to that
of a chronic disease (Hazra, Siberry & Mofenson, 2010).

Due to the availability of medicines to prevent perinatally transmitted HIV, the number of new cases of perinatally acquired infections has significantly decreased since 1995. Currently, there are approximately 8,500 children living with HIV in the U.S. (Hazra, Siberry & Mofenson, 2010). However, the actual prevalence of perinatally infected children living in the U.S. may be much larger. As of April, 2008, the CDC surveillance data includes all 50 states, the District of Columbia and 6 dependent areas: American Samoa, Guam, the Northern Mariana Islands, Palau, Puerto Rico, and the U.S. Virgin Islands-used the same confidential name-based reporting standards to collect HIV surveillance data. Prior to this, only thirty-three states and five dependent areas used confidential name-based reporting to collect HIV infection data. The different methods of collecting data posed a challenge when compiling national data. While the CDC has worked to ensure the validity of this updated data, stabilization of the data collection and adjustment of the data in order to monitor trends is ongoing (CDC, 2012c). Until the surveillance includes reporting from all states and dependent areas and includes more current data, the numbers of HIV infected individuals is underrepresented.

Research indicates that HIV positive women are particularly distressed by demands placed by family and report greater symptoms of distress and substance use than women with other chronic illnesses (Hudson, Lee, Miramontes & Portillo, 2001). That is, the biological impact of their condition often complicates lives that are constrained by profound personal, social and economic issues. New therapies increase care giving and self-care demands, which can isolate these families and cause symptoms of psychosocial distress in family members (Hudson et al. 2001; Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002). Thus, traditional family caregiving responsibilities
of HIV-infected women can be complicated by lack of resources and depression. In addition, compromised psychosocial functioning may increase their struggle with their day-to-day caregiving responsibilities (Hackl, Somlai, Kelly, Kalichman, 1997). Hackl and colleagues (1997) study illustrates that primary concerns of women, maternal quality of life including physical and psychosocial functioning and psychosocial functioning and family management (caretaking roles, social support needs) are consistent with those proposed in this study. How women manage their illness is important to their own self-care and needs to be considered when studying both their self-care and family management.

Many studies describe the subjective experiences of families of children with chronic conditions of childhood, and ways families actively manage these conditions. Fewer studies (Cohen, 1994; Ledlie, 1999; Mellins & Ehrhardt, 1994; Santacroce, Deatrick & Ledlie, 2002) describe the experiences of families with a child who has HIV infection. Less emphasis is placed on how biological mothers, who themselves are infected with HIV, manage their children’s treatment for HIV. Santacroce and colleagues (2002) noted that the “mothers’ perspectives on managing their children’s treatment for HIV was inextricably linked to their own first-hand experience of being a person with HIV” (p. 252). Santacroce’s results imply that mothers’ make decisions regarding their child’s care based on their own experiences with HIV in their own sociocultural context. In this study, mothers discussed knowing the harm caused by the virus having experienced it first hand and took aggressive approaches to protect their children. As a result, mothers approached managing their child’s condition with aggressive medical management and by protecting their children’s emotions by highlighting their roles as a mother and their concern for their children. The process through which biological mothers manage their children’s medical treatment for HIV is interwoven with how mothers manage related
psychosocial issues.

Mothers with chronic illness experience an ongoing struggle to balance their own health concerns with the demands and needs of their families (Hackl, et al., 1997). Social role experiences may be an important factor in a woman’s adaptation to chronic illness (Plach, Stevens & Heidrich, 2006). In women who are HIV infected, nearly all women experienced demands of illness such as limitations in physical functioning, HIV associated symptoms, coexisting health problems, and high levels of symptomatology (Plach, et al., 2006). Perceived family support however, reduces loneliness, stress and presence of depressive symptoms (Hudson, et al., 2001; Serovich, Kimberly, Mosack & Lewis 2001). In fact, Sowell and colleagues (1997) note that social and psychological factors are important influences on quality of life of HIV infected women. Thorne, Paterson & Russell (2003) noted that the HIV associated stigma and related emotional and social issues affect the day-to-day self-management of the disease for persons with HIV and their families. Of particular interest to the investigator is how mothers with HIV perceive their own quality of life and how this may in turn influence the way they are able to manage their child’s illness, that is, how mothers with HIV care for their children when they must attend to the needs of their own illness (i.e. how they perform self-care in the context of parenting). Examining potentially influencing factors such as mother’s quality of life, mother’s self-care and psychosocial factors such as mother’s depression are important in understanding how a mother manages her child’s chronic illness in light of her own illness. Illness related variables, such as laboratory values of CD4 and HIV viral load, which clinically reflect HIV disease severity are additional factors to consider. Ultimately these influencing maternal factors may affect the child’s outcome (CD4 count and HIV Viral Load). How this applies to families who have both a chronically ill mother and chronically ill child requires further study.
Sociocultural Aspects of HIV

The sociocultural issues experienced by mothers and their children with HIV are particularly notable. Mothers and their children suffer from health disparities in their ability to access HIV medical care and support services (Berry, Bloom, Foley, & Palfrey, 2010). In a review of the literature, serious racial and ethnic health and health care inequities were identified in the mid 1980’s, which persist to the present. Racial and ethnic populations have been disproportionately affected by the HIV epidemic in the U.S. Although African-American and Latino persons represent about one-quarter of the country’s population, more than half of new AIDS cases reported to CDC are among these populations. Among children, the racial and ethnic disparities among those infected are even more dramatic. Of the perinatally infected persons living with HIV/AIDS at the end of 2005, an estimated 66% were Black (non-Hispanic), and an estimated 20% were Hispanic/Latino. High rates of poverty also exist among families with HIV (CDC, 2012a; CDC 2012b; CDC 2012c).

Urban areas in the U.S. are particularly disproportionately affected in part because residents of these areas have limited social mobility and as such have relatively insular social and sexual networks where transmission patterns are concentrated and amplify the spread within defined geographic areas (El-Sadr, Mayer & Hodder, 2010). Further, many women face significant discrimination as a result of race and ethnicity and gender, and they suffer disproportionately from poverty, low health literacy, and lack of access to high-quality HIV care. As a consequence, women living with HIV may delay entry into care and experience poor outcomes (Aziz & Smith, 2011). Consequently, HIV continues to have a significant presence in the U.S. and the effects of the disease will continue to affect individuals and families.
A major sociocultural consideration of HIV is the unyielding stigma associated with the disease. For many women, the disease-associated stigma has potential implications in regards to their own self-care and in their role as a mother or caregiver. Because women who are HIV infected are living longer, many follow the developmental trajectory of having children and raising families; however, in addition to their HIV status being attributed to their “poor” choices, women can also be blamed for becoming pregnant and transmitting the virus to their unborn children. They can be further discredited because of the eventual lethality of the illness. Because of this, managing the demands of their own stigmatizing illness and possibly the illness of offspring, chronic illness often consumes much of their lives as well as the lives of their families and becomes burdensome. Women of racial and ethnic minority groups are especially vulnerable to discrimination because of the stigma associated with HIV, as well as their race, gender and class status and alienating factors such as poverty (Wingood, et al, 2007). Like any other chronic illness, management of HIV must be incorporated into daily functioning to obtain good outcomes. How a woman perceives stigma has great implications for her own physical and psychological health and potentially for her children as well.

Families’ Experiences with HIV

HIV has been called a disease of the family in that it is often multigenerational in the manner in which it is transmitted. Treatment of HIV is complex and demanding for the family. Families living with HIV manage a multitude of problems. These include but are not limited to: 1) trauma and fear about recurring illness episodes; 2) social isolation and stigma from family and community; 3) psychological and emotional issues including depression, guilt and hopelessness; 4) difficulty in maintaining normalcy in day to day life; 5) uncertainty and unpredictability of the illness; 6) potential lack of access to care
and financial issues; and 7) potential for need to treat co-morbid conditions including substance use (Pequegnat & Bray, 1997).

Research has identified that being a parent is important to the majority of women with chronic illnesses, such as HIV and mental illness, despite the potential significant self-care demands of her own illness and those of her child’s illness (Ackerson, 2003a; Ackerson, 2003b; Nicholson & Biebel, 2002). Parents and particularly mothers who are viewed as the primary caregivers for their children in most cases have a valued social role. Many women who are HIV infected, however, are affected by other illnesses including possible addictions and progression of their HIV, which affects their physical and mental ability to care for themselves and their children (Schable, et al, 1995). Acknowledging the potential indirect effects of maternal drug and alcohol involvement on child health outcomes in HIV-affected children, this research will limit its focus to key factors that may directly influence children’s health care outcomes (i.e. illness related variables- CD4 count and HIV viral load, which are reflective of disease severity) including maternal factors (quality of life, depression, self-care and illness related factors, HIV viral load) and family factors (condition management ability, family life difficulty and condition management effort).

**The Importance of Studying the Mother and Child with Chronic Illness**

Considerable research has been conducted regarding the impact of a child’s chronic illness on the family and its functioning. However, a gap in the literature exists in the area of family management when the care giving parent is also chronically ill.

Often, HIV positive mothers are the sole caregivers for their children. Many are unmarried and have multiple young children in their care, some of whom are HIV infected, and face many challenges (Michaels & Levine, 1992; Schable et al., 1995;
Tompkins, Henker, Whalen, Axelrod & Comer, 1999). Thus, they may give priority to the caregiving needs of their children while ignoring their own health (Tufts, Wessell, & Kearney, 2010). Women with HIV face unique challenges as their own illness may disrupt their role as a family caregiver (Sowell, Seals, Moneyham, Demi, Cohen & Brake, 1997; Webel & Higgins, 2012). Caregiving responsibilities for dependent children have been associated with decreased adherence to self-care regimens including taking prescribed medication (Holstad, Dilorio, & Magowe, 2006; Tufts, Wessell, & Kearney, 2010). Women infected with HIV may face years of health decline and the eventual onset of a number of debilitating opportunistic infections leading to loss of physical functioning and eventually death. Women may also face social isolation due to stigma associated with HIV (Moneyham, Seals, Demi, Cohen & Guillory, 1996; Sowell, Lowenstein, Moneyham, Demi, Mizuno & Seals, 1997). The combination and interaction of these factors can affect the woman’s ability to promote and maintain her own health and well-being and can have the potential to influence quality of life (Sowell et al, 1997) and her ability to care for herself and her children.

**Defining Family Management**

Research has identified factors that affect how individuals deal with their own chronic illnesses. Included in this literature is how individuals and families manage the illness of others, as in the case of a mother providing care for her chronically ill child. The primary concepts measured in studies of families living with chronic illness include quality of life which may include perceived physical functioning and perceived psychosocial functioning including mental health, self-care, family functioning, and family management (Bennett Murphy, Koranyi, Crim & Whited, 1999; Catz, Gore-Felton, & McClure, 2002; Chou & Holzemer, 2004; Knafl & Deatrick, 2003; Murphy, Greenwell & Hoffman, 2002;
Family management describes the family processes that guide illness management or how the family members care for an ill family member (Knafl & Deatrick, 2003). A model was developed in 2003 by Knafl and Deatrick and has been refined to study the concept of family management. The Family Management Style Framework is a framework that has been used to describe family response to health related challenges in the context of their child's chronic conditions and how these are managed (Knafl, Deatrick & Havill, 2012). The framework includes eight dimensions comprising its three components (Definition of the Situation, Management Behaviors and Perceived Consequences) (Knafl & Deatrick, 2003; Knafl, Deatrick & Havill, 2012).

Current research supports the relevance of the framework dimensions and includes the following eight dimensions as comprising family management: 1) child identity (parents’ view of the child and the extent to which those views focus on the condition of normalcy and capabilities or vulnerabilities); 2) view of condition (parental beliefs about the cause, seriousness, predictability and course of the condition); 3) management mindset (parental views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively) 4) parental mutuality (parent’s beliefs about the extent to which they have shared or discrepant views of the child, the illness, their parenting philosophy, and their approach to condition management); 5) Parenting philosophy (parent’s goals, priorities, values, and beliefs that guide the overall approach and specific strategies for condition management); 6) management approach (parent’s assessment of the extent to which they and their child have developed a routine and related strategies for management of the condition and incorporating it into everyday life) 7) Family Focus (parent’s assessment of and satisfaction with how condition
management has been incorporated into family life) and 8) future expectation (parent’s assessment of the implications of the condition for their child’s and their family’s future (Knafl, Deatrick, Havill, 2012).

The current study focused on the family management mindset dimension which included ability and effort in managing the child’s condition and included the difficulty in managing the child’s condition in the context of family life. These three aspects of family management were expected to be associated with the child’s outcomes. Understanding how families manage the requirements of illness and family life is an essential for designing effective interventions so that individuals and the family as a whole can achieve better outcomes. Pediatric nurses have a primary responsibility for children’s outcomes but must do so in a way to insure optimal maternal outcomes. Thus, designing research that is sensitive to the health outcomes of HIV-infected children, while being cognizant of the needs of their HIV-infected mothers, is an important step toward realizing positive outcomes for not only children but also their caregivers and families.

**Purpose of the Study**

The purpose of the study is to describe and analyze factors that may predict children’s health outcomes when both children and their mothers are HIV infected. This study included maternal factors identified in the current literature, which may affect child outcomes. These maternal factors include quality of life, capacity for self-care within the context of being a parent, illness related disease severity (CD4 count and HIV viral load), depression and family management factors (condition management ability, family life difficulty and condition management effort). Identification of the needs of the mother with HIV (maternal factors) and how these maternal factors influence family
management of the child’s illness inform development of interventions that may help mothers and families more successfully manage their children’s HIV illness.

In order to design effective interventions, we must understand how families manage the requirements of illness (HIV) within family life and acknowledge the complexity of the physical, psychosocial, illness (HIV) related and family factors that affect the outcome of successful management of the child’s HIV disease. While it is noted that stigma plays a potentially significant role in self and family management, the proposed Model (Figure 1) for the study measures intra-family processes. A major extra-family process, stigma, will also be examined by an exploratory aim.
* Mother’s CD4 count was removed from the Model for this study (refer to Chapter 4 for discussion of Model revision)

**Figure 1:** Vincent Family and Self-care Management of HIV Infected Women and their HIV Infected Children Model (Vincent Model)
**Specific Aims**

The overall goal of the study was to examine the role of family management as a potential mediator in the relationship between maternal factors and children’s clinical outcomes for women and their children infected with HIV.

**Primary Aims**

*Specific Aim 1*
To evaluate the relationship between maternal factors and family management.

*Hypothesis 1a:* Mothers who report poorer quality of life, higher levels of depression and poorer self-care will report **decreased ability** in managing their children’s condition.

*Hypothesis 1b:* Mothers who report poorer quality of life, higher levels of depression and poorer self-care will report **increased difficulty** in managing their children’s condition.

*Hypothesis 1c:* Mothers who report poorer quality of life, higher levels of depression and poorer self-care will report **increased effort** in managing their children’s condition.

*Specific Aim 2*
To evaluate the relationship between the maternal factors and child outcomes.

*Hypothesis 2:* Children whose mothers who report poorer quality of life, higher levels of depression, and poorer self-care will have decreased CD4 counts and high viral load measures.

*Specific Aim 3*
To evaluate the relationship between family management and child outcomes.

*Hypothesis 3a:* Children whose mothers report increased effort in family management have decreased CD4 counts and high viral load measures.

*Hypothesis 3b:* Children whose mothers report increased difficulty in family management have decreased CD4 counts and high viral load measures.
Hypothesis 3c: Children whose mothers report less ability in family management have decreased CD4 counts and high viral load measures.

Specific Aim 4

To evaluate whether the relationship between maternal factors and the child outcomes are attenuated by the presence of family management.

Hypothesis 4: Family management will mediate the relationship between maternal factors and child clinical outcomes.

Secondary Aim

To describe maternal perceptions of stigma regarding: consequences of others knowing their HIV status, disclosure, self-image, and public perception of HIV.

Proposed Conceptual Model Supporting the Study

For the current study, we proposed a Model (Figure 1) constructed with the concepts of interest and conceptually grounded in the current chronic illness, family management and HIV literature. The Model focused on HIV infected mothers and HIV infected children as a beginning point for this study. The population of interest for this study is mothers who have a chronic illness (HIV) and who have children (18 years of age or younger) with the same chronic illness (HIV). Figure 1 lists variables of interest. The measures used to assess the variables are listed in Appendix A. As shown in Figure 1, maternal factors which are perceived to influence the management of the child’s illness include the following variables of interest: mother’s quality of life, mother’s self-care (capacity for self-care within the context of being a parent), mother’s disease severity (HIV viral load), and mother’s depression. Family Management includes family management of the child’s illness from the mother’s perspective. More specifically, this
concept examines mother’s report of condition management ability, family life difficulty and condition management effort. The outcome measure of the Model includes the child outcome specifically illness related variables which are reflective of the child’s disease severity (CD4 count and HIV viral load). The Model together assumed that maternal factors affect family management of the child’s illness and ultimately the physiologic outcomes in the child (i.e. CD4 count and HIV viral load) which are reflective of disease severity. The study examined how these concepts in the Model may be related. The pervasive concept of stigma has been strongly associated with HIV disease. While stigma is not directly incorporated into the Model, how women perceive stigma will be explored. Overall, the role of family in chronic illness has been viewed as important in research. However, this research intends to add to the body of literature that reinforces the importance of family in this regard.

The proposed Model assumed: 1) multiple, simultaneous, intra-family processes and 2) interplay among these variables. The overall framework assists in understanding how mothers perceive their quality of life, self-care, mental health (depression) and management of the child’s illness within the context of the family. Examining these maternal factors is important in understanding how they may affect how mothers manage their children’s chronic conditions and ultimately the children’s outcome. The chapters that follow will thoroughly describe the phenomena of interest, as well as the study, which has been designed to address this important gap in the science.
CHAPTER 2

Background and Significance: A Literature Review

Introduction

The purpose of the study is to describe and analyze factors that may predict children’s health outcomes when both children and their mothers are HIV infected. In this study, we examined the role of family management of the child’s condition as a potential mediator in the relationship between maternal factors and child outcomes as illustrated in Figure 1. This chapter provides an orienting background regarding family in the context of chronic illness as well as background and significance of the management of HIV in obtaining good clinical outcomes. Three bodies of work guided the study and development of the concepts of interest: (1) chronic illness in women, specifically mothers, which includes quality of life (i.e. physical functioning and psychosocial functioning) and self-care; (2) childhood chronic illness and child functioning; and (3) family management of a child’s chronic illness, which includes the mother’s role in managing the child’s illness within the context of ongoing family life. These bodies of literature support the conceptual structure of the Model for the study (Figure 1). The HIV literature and the broader chronic illness literature has been referenced, as necessary. The chapter will conclude with a discussion of current gaps in the literature and implications of the current study.

Defining Family

What is family? Family is generally defined as a group of persons living together who form a household and may have a common ancestry (Dictionary.com, 2012). A nuclear
family that includes a mother, father and children was the traditional definition of family but, in the present time, family is often self-defined. Families take on many forms. There may, in fact, be no biologic ties. Families can vary by culture and sociocultural experiences. The family in contemporary America may be defined as a group of individuals who by birth, adoption, marriage or declared commitment share deep personal connections and are mutually entitled to receive, and obligated to provide support of various kinds. As more people live in nontraditional arrangements, the gap between their needs and interests and official designations of family widens. In fact, AIDS has accelerated this change, affecting legal definitions, medical decisions and questions of housing and child custody (Levine, 1990). Because this is a study concerning biological transmission of HIV, in this study, family is defined as mothers and their children, including those who are characterized by (1) biological status (having given birth to the child); and (2) provide the primary care-giving for the child with the chronic illness (i.e. living with the biological mother the majority of the time).

**Managing HIV and Clinical Outcomes**

HIV disease was identified only 30 years ago. Since that time, the prevention of HIV, management of HIV and finding a cure have been the focus of study (Diffenbach & Fauci, 2011). As a result of the improved pharmacologic and health care treatment, HIV has been transformed from a debilitating, fatal disease to one of a more chronic nature (Uphold & Mkanta, 2005). The disease requires day-to-day management including use of daily medications and adequate nutrition to prevent the virus from weakening or destroying the immune system.

HIV viral load (the laboratory measure of HIV in the blood plasma) and CD4 count (the laboratory measure of a type of white blood cell which indicates immune
function) are reflective of how well controlled the virus is in the blood plasma. Persons infected with HIV generally have better clinical outcomes when they take daily antiretroviral medications and, as a result, maintain low or undetectable viral load and maintain CD4 counts which reflect a functioning immune system. In addition, studies have shown that 95% or greater adherence to medication is necessary for good clinical outcomes (Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006). Thus, self-care is paramount in good clinical outcomes. In addition, the care of the family for those affected is also important. Thus, more study is needed to understand family management. This research focused on the mother’s response, including self-care and family management of her HIV infected child. A review of the literature regarding these responses follows. The review included studies focused on women and sometimes more specifically, women as mothers. When appropriate, the two will be differentiated.

**Individual and family responses to chronic illness: What is known about chronic illness in women and mothers**

The body of literature regarding chronic conditions such as HIV has traditionally highlighted the perspectives of individuals with chronic conditions rather than how the family (in whichever form defined) manages the condition. The individual’s responses have varied according to physical health; psychosocial factors such as anxiety or depression; availability of support from family, friends and others; concrete resources; the degree of illness in the child and mother; co-existing substance use or mental health issues; spiritual strengths; and, beliefs about illness (Byrne & Honig, 2006; Coleman & Holzemer, 1999; Hudson, Lee & Portillo, 2003; Lesar & Maldonado, 1996; Pequegnat & Bray, 1997; Robinson, 2004).

Women, by virtue of their societal roles, are expected to take on multiple tasks each day. When a woman has a chronic illness, the list of tasks becomes expansive. The
task list includes, managing household chores, caring for self and other family members, managing complex medication regimens, coping with multiple losses; coping with disease related stigma and discrimination, managing available resources, garnering new resources, and possibly dealing with addiction or recovery from addiction (Bennett Murphy et al., 1999; Ingram & Hutchinson, 2000; McIntosh & Rosselli, 2012; Moneyham, Sowell, Seals & Demi, 2000). Most typically, mothers put their children’s illnesses first and in most cases do not attend to self-care (Abell, Ryan & Kamata, 2006; Holstad, Dilorio & Magowe, 2006; Tufts, Wessell & Kearney, 2010). Factors such as management of basic survival needs (food, clothing and shelter) for the family can be all consuming leaving little time to manage one’s own illness and thus, children’s care is prioritized.

Another essential factor to consider is that illness is culturally shaped. How illness is perceived, experienced and responded to is based on the explanation of sickness, explanations specific to the social positions individuals occupy and systems of meaning individuals employ (Kleinman, Eisenberg & Good, 2006). Cultural beliefs also contribute to how individuals communicate about health problems, the manner in which symptoms are presented, when and whom individuals seek out for care, how long the individual stays in care and how that care is evaluated (Kleinman, 1988; Kleinman, Eisenberg & Good, 2006). How mothers respond to illness for themselves and their family members, particularly their children, may differ based on these cultural beliefs. HIV is a striking example of a disease where cultural considerations play a major role in how the disease is interpreted both from an individual and social perspective.

Since the beginning of the HIV pandemic, culture has been an explanatory force in understanding power and its ramifications for prevention and treatment of the disease. The relationship between culture and HIV is complex. The literature gives much
consideration to the role of culture and cultural norms in such areas as gender roles and power relations. How culture may increase risk for infection as well as how the HIV epidemic has been shaped by sexual relationships, family structure, socioeconomic status and race has also been studied (UNESCO, 2012). Cultural norms influence sexual practices and gender inequalities which put persons at risk for HIV and its sequelae. Thus, culture influences decision making regarding when or if to seek HIV testing, counseling or treatment, and engaging in risky behaviors (AAWH, 2012).

HIV is a chronic illness accompanied by a host of demands ranging from social stigma to uncertainty of illness progression (Ball, Tannenbaum, Armistead & Maguen, et al., 2002). For women living with HIV, the biological impact of the illness interacts with profound personal, social and economic constraints. These demands are a crucial focus of study on how HIV affects women (Ball, et al., 2002). HIV infection is usually detected in women at either the presentation of advanced disease (AIDS) or when screening is done during pregnancy (Greenblatt, 2011; Waters, Fisher, Anderson, Wood, Delpech, Hill, et al., 2011). Therefore, many women discover they are HIV infected during their childbearing years, are raising children, and may be at especially high risk for emotional distress due to limited access to care and social support (Greenblatt, 2011; Melnick, et al., 1994). Women with HIV infection experience significant stresses grounded in poverty, discrimination, substance abuse and the social role as caregivers and mothers (Bova, 2001; Hellinger, 1993). Improvements in HIV treatment and care have resulted in women, including mothers, living longer. However, they are still shadowed by compromised health, reduced finances, decreased energy, increased isolation and depleted resources (Keigher, Zabler, Robinson, Fernandez & Stevens, 2005). HIV infected women are at higher risk for poor mental health and extensive physical symptoms such as pain, fever and changes in body fat distribution and weight loss.
(Dodd, et al, 2001; Holzemer, 2002; Holzemer, Hudson, Kirksey, Hamilton & Bakken, 2001; Hudson, Kirksey & Holzemer, 2004). As these physical and psychosocial problems are inextricably linked for mothers with HIV, a better understanding of how they manage their children’s HIV is imperative.

**Quality of Life**

Transformation of HIV disease into a manageable chronic condition has shifted focus to quality of life of persons living with HIV and the psychological stress of the condition and its treatment (Edwards, Irving, Amutah, & Sydnor, 2012; Vyavaharkar, et al. 2011). Assessment of quality of life is important in documenting burden of disease, evaluating treatments, tracking health related changes over time and gauging returns in health care investments (Vyavaharkar, Moneyham, Murdaugh & Tavakoli, 2012). In recent years, the constellation of factors that encompass an individual’s quality of life has become an increasing focus within chronic illness literature. Many variables have been identified as affecting the way in which women experience and deal with their own chronic illness. Physical functioning, mental health functioning, and social role functioning are among the important dimensions of a person’s quality of life (Chou & Holzemer, 2004; Gielen, McDonnell, Wu, O’Campo & Faden, 2001; Wu & Rubin, 1992).

The chronic illness literature, inclusive of the HIV/AIDS literature, is strongly suggestive that quality of life (QOL) and more specifically, health-related quality of life (HRQOL) has a prominent place in how an individual perceives the effect of chronic illness on their daily functioning. HRQOL is a multidimensional concept that encompasses a broad range of physical and psychological characteristics and limitations that describe how the individual functions, performs social roles, and derives a sense of
well-being across all domains of life and satisfaction from doing so (DeCivita, Regier, Alamgir, Anis, Fitzgerald, & Marra, 2005; Farquhar, 1995; Tsasis, 2000). A review of these quality of life dimensions including symptoms and physical functioning in HIV and psychosocial functioning in HIV follows.

Symptoms and physical functioning in HIV

Women with chronic conditions experience physical and psychosocial aspects of condition management. Plach, et al., (2006) suggests that physical functioning and psychosocial factors are inter-related; quality of experiences within social roles influences adaptation to chronic illness and proposes that high social role quality can mediate and moderate the effect of physical health on psychological well-being.

Physical functioning is defined in this study as physiologic symptoms, which are subjective experiences reflecting changes in a person’s biopsychosocial function, sensation and cognition (Dodd, et al, 2001). In HIV disease, HIV viral load and CD4 count, are laboratory markers which assist health care providers in assessing the patient’s adherence to medications. They are not reflective of the true and perceived patient experience with the condition. While laboratory markers are seen as the clinical standard for patient management, the patient’s perception of symptomatology and well-being must also be considered (Holzemer, 2002) and incorporated into the treatment plan. Patients are often considered symptom free when they have a low HIV viral load (indicating a low amount of detectable HIV virus in the blood plasma) and a high or stable CD4 count (which is seen as the primary marker for immune function in HIV disease). Studies have shown that patients’ experiences vary based on their HIV
disease as well as the antiretroviral medications used to treat the illness, yet health care
providers may assume that the patient is symptom free based solely on laboratory
values. Additionally, when a patient has a symptom, he or she may associate the
symptom with symptoms that represent something distressing (i.e. association of fatigue
with disability and association of fatigue with inability to take medicine) (Chou &
Holzemer, 2004; Holzemer, 2002; Hudson, Lee, & Portillo, 2003; Kemppainen, et al.,
2006; Sousa, Holzemer, Henry & Slaughter, 1999; Voss, 2005).

Symptoms in HIV disease can be caused by HIV infection itself, by the side effects of
medications and treatments, or by the associated opportunistic infections (Hudson, et
al., 2003; Hudson, Kirksey & Holzemer, 2004; Shumaker, Ellis & Naughton, 1997).
Symptoms are often unpredictable due to their dynamic nature which can make
symptoms distressing and frustrating. Studies show that people living with HIV/AIDS
experience multiple physical symptoms including fever, diarrhea, headache, shortness of
breath, fatigue, sleep disturbances, weakness, poor appetite, wasting,
dyspnea/shortness of breath and pain (Matthews, et al, 2000; Chou & Holzemer, 2004;
Holzemer, 2002; VanServellen, Sarna & Jablonski,1998) which then influence their
physical and mental functioning. Determining which symptoms affect a patient’s physical
functioning, how they perceive these symptoms, and the personal meaning of these
symptoms are an essential part of assisting a patient with managing these symptoms,
which then may help promote better self-management and better self-care.

Women with symptomatic HIV disease, like men, experience disruption in physical
health status and functional decline (Van Servellen, et al., 1998). In an exploration of
the relationship between self-reported symptom experience (defined as symptom
frequency and symptom distress) and symptom outcome (defined as functional status)
among HIV-infected women, studies have found that women who were distressed were
at increased risk for depression and had a moderate level of physical functioning. These findings were particularly true for women who reported a higher level of symptomatology such as trouble falling asleep, weakness, numbness, tingling and poor appetite (Hudson, Lee & Portillo, 2003; Sousa, et al., 1995). As a consequence of these physical problems of progressive loss of physical function and recurrent symptoms of fatigue, breathlessness, and fevers, the illness restricts women’s social and daily activities and can give rise to feelings of emotional distress and impaired psychological well-being (Plach et al., 2006). There is ample evidence in the literature that there is a connection between physical and psychosocial functioning in chronic illness.

**Psychosocial functioning in HIV** Psychosocial functioning is defined as how psychological symptoms such as depression and anxiety and social adjustment affect an individual’s day to day functioning with chronic illness. For the purposes of this study, the individual is a woman who is a biologic mother and who has HIV. Physical symptoms resulting from HIV infection have an impact on psychosocial variables such as parenting, employment, mental health and social roles. The psychosocial aspects of HIV/AIDS have received attention because HIV disease, similar to other life-threatening illnesses, challenges mothers to evaluate their changing quality of life (Van Servellen, et al. 1998). In fact, cognitive evaluation or appraisal of illness along with social support and symptom experience are important factors influencing psychosocial adjustment and found that appraisal explained 12% of the variance in adjustment to HIV (Bova, 2001).

The profound life altering effects of chronic conditions such as diabetes, multiple sclerosis and HIV do not dissipate quickly or easily (Emery, 2003). The effects of HIV infection have some unique qualities but in many ways mirror those of other chronic illnesses. Studies of women with other chronic conditions suggest that the quality of
experiences within their social roles is an important factor in adaptation to chronic illness and that the quality of social roles can mediate and moderate the effect of physical health on psychological well-being (Plach, et al., 2004; Plach & Heidrich, 2002; Plach, Heidrich & Waite, 2003). Social role quality, physical health and psychological well-being in HIV infected women has been explored (Plach, et al., 2006). Investigators concluded nearly all HIV-positive women experienced limitations in physical functioning, a myriad of HIV symptoms, coexisting health problems, and high levels of depressive symptomatology (Plach, et al., 2006). The study supported similar studies of women with HIV (Hudson, et al., 2001; Miles, Gillespie, & Holditch Davis, 2001; Moneyham, et al., 2000). Another study noted that levels of depression, stress and anxiety were elevated in HIV positive persons relative to levels found in community normative populations (Catz, Gore-Felton & McClure 2002). While the studies cannot be over generalized due to the small populations in which they were conducted, the information lays the groundwork for further study.

Psychosocial problems including emotional distress (e.g. feelings of fear and sadness) and more serious conditions (e.g. clinical depression and anxiety) have become a familiar part of the AIDS experience (Van Servellen, Sarna, Nyamanthi, Padilla, Brecht & Jablonski, 1998). Individuals diagnosed with HIV infection experience symptoms of anxiety and depression; however, this research is based primarily in research on men (Catz, et al, 2003). Depression is a common co-morbidity of HIV infection with prevalence estimates of major depressive disorder among persons living with HIV ranging from 20% to 37%, compared to 10% in the general population (Bing, et al., 2001; Simoni, et. al, 2011; Valente, 2003). Mental illness, notably depression, is highly prevalent in HIV infected persons and has been associated with reduced adherence and worse clinical outcomes (Buchacz, Rangel, Blacher & Brooks, 2008;
Horberg, Silverberg, Hurley, et al, 2008; Lima, Geller, Bangsberg, et al, 2007). Women’s psychological well-being or lack thereof (i.e. psychological distress) are issues of particular importance (Catz, et al. 2002). However, more studies are needed to describe psychological sequelae and coping skills among HIV positive women who are mothers. Recent studies have shown that women experience even higher levels of psychological distress, which can be attributed to contextual and sociocultural issues of responsibility with childcare and care for others, stigma and social isolation (Catz, et. al., 2003). In addition, research indicates that HIV infected women are at risk for poor psychological adjustment (Murphy, et al, 2002).

HIV positive women, who have HIV infected children face the strain of caring for a sick child while also managing their own illness (Bachanas, Kullgren, Schwartz, McDaniel, Smith & Neisheim, 2001). Previous studies show that mothers who are HIV infected have high levels of psychological distress and depressive symptoms, even when compared to mothers with similar backgrounds (Biggar & Forehand, 1998; Brackis-Cott, Mellins, Dolezal & Spiegel,2007; Dorsey, Chance, Forehand, Morse & Morse, 1999; Miles, Burchinal, Holditch-Davis, Wasilweski & Christian, 1997).

Mothers’ psychological adjustment is a significant predictor of their children’s emotional and behavioral functioning (Miles, et al, 1997). High rates of co-morbid psychiatric and substance abuse disorders among HIV-infected women, the potential heritability of these disorders, as well as family and social stressors place children of these women at high risk for their own mental health problems (Bennett Murphy et al, 1999; Brackis-Cott, et al., 2007). We know that many HIV infected women are primary caregivers for their children. In a meta-analytic review, it was found that despite antiretroviral treatment advances, mental health outcomes continue to be poor and these outcomes were predicted by psychosocial stress and HIV/AIDS symptoms. Also, there
are social factors, which play a major role in women’s depression. HIV seropositivity was positively correlated with depression and negatively correlated with social support and effective family function (McIntosh & Rosselli, 2012). The results of these studies highlight the importance of identifying these issues and treating the comorbid conditions to provide a foundation for optimal self-care and family management.

Disclosure

Decades later, fear of stigma and ignorance surrounding transmission of the disease is still present. Disclosing one’s HIV status is complex and poses unique difficulties for families with HIV (Bennett Murphy, et al, 1999). Thus, it is possible that disclosure could be a confounding factor in the Model potentially affecting maternal factors, family management and subsequently child outcomes. Disclosure is defined as the act of revealing information (Dictionary.com, 2012). Disclosure is sometimes a process, occurring over time. There are many reasons why individuals do not disclose their HIV infection status or the HIV infection status of their child to other family members. Among these reasons is fear of rejection, fear of isolation, worry about a child knowing how a parent was infected (i.e. risk behaviors), social stigma, the life-threatening nature of the illness, and loss of other family members (Instone, 2000). Sharing the diagnosis may subject the disclosing individual to undue stress. The intensity with which parents and guardians resist disclosure often surprises pediatric clinicians when the issue is raised (Instone, 2000). Disclosure of the HIV diagnosis in and of itself has the potential to change individual and family relationships. HIV infected women have to weigh how disclosing their own HIV diagnosis to a partner, family member or friend will affect that
relationship. The issue becomes even more intense when a child is involved. In fact, mothers living with HIV report that the decision regarding communication of illness related information to their children as one of their major concerns (Kirshenbaum & Nevid, 2002).

Among families directly affected by HIV, mothers who disclosed their own HIV status to their children experienced greater depressive symptomatology than those who did not and children who had been disclosed to were more likely to score in the clinically depressed range in depression measures than those who did not know (Brackis-Cott, et al, 2007). There is ample evidence in the literature supporting the process of disclosing to one’s child (De Matteo, et al., 2002; Ledlie, 1999; Lipson, 1994; Wiener, Battles & Heilman, 2000). Disclosure to children takes place within historical and social contexts that include parent-child relationships, family dynamics, relationship with the health care system, current knowledge of HIV disease and belief systems (De Matteo, et al., 2002). One study showed that parents keep the diagnosis secret between 2-8 years after diagnosis (Instone, 2000). Disclosure was also related to whether a mother thought she could manage her child’s well-being. Thus, if the mother thought she could effectively manage, she was less likely to disclose (Bennett Murphy, et al., 1999). Disclosing HIV status to a child becomes important as they age so that they can understand the disease and disease management and take an active part in self management which includes taking medications, knowing when to call the doctor and working together with their parent or caregiver to eventually, when able, become independent (Hazra, Siberry & Mofenson, 2010). It is clear in the literature that disclosing HIV status, with all of its potential risks and benefits, requires support from family and health care providers.

Disclosure is an ongoing and dynamic process. Caregiver readiness, conditions and reciprocal responses are factors that were identified by caregivers and children that
influence the timing of diagnosis disclosure in families whose children acquired HIV perinatally (Ledlie, 1999). The stress of secrecy ultimately becomes a barrier to health care, employment and relationships (Carr & Gramling, 2004). Women, particularly mothers, may experience an added burden when disclosing HIV because of the vertical mechanism through which the disease is transmitted from mother to child. Thus, disclosure and stigma are intertwined and a complex part of living with HIV disease.

**Stigma and Discrimination**

The stigma associated with HIV dates back to the beginning of the epidemic when the first group of persons identified to have the disease were gay men (CDC, 2012b; CDC 2012c). Historically, the behaviors associated with the acquisition of HIV lent to the public perception that the disease was deserved by the men who participated in the acts that put them at risk for infection. These risk behaviors were not considered part of the mainstream and perceived by many in society as deserved because they were self-inflicted (Shilts, 1988). AIDS had seemed a comfortably distant threat to most of those who had heard of it before. It was seen by society as “the misfortune of people who fit into the rather distinct classes of outcast social pariahs” (Shilts, 1988, xxi). Before long, HIV rapidly became a disease that has affected every population group but particularly other marginalized groups, specifically women of color and adolescents (Cederbaum, 2008; CDC, 2012b; UNAIDS, 2008). As the pandemic continues to unfold in the United States and internationally, the behaviors associated with disease acquisition, primarily sexual intercourse and injecting drug use means that HIV often results in discrimination in the workplace and by society in general. Women, in particular, did not consider themselves at risk for contracting HIV as this was a disease that happened to ‘others’
(Carr & Gramling, 2004, p. 30). When women became one of the ‘others’, the disease demographic changed.

HIV related stigma is a complex concept that lies within a person’s attitudes and perceptions (Morrison, 2006). Stigma can effectively isolate persons living with HIV which, in turn, can further compromise physical, psychological, and social health (Brouard & Wills, 2006; Sayles, Ryan, Silver, Sarkisian & Cunningham, 2007) and depression, particularly in women (Clark, Lindner, Armistead, & Austin, 2003; Prachakul, Grant & Keltner, 2007). The fear of stigma becomes so overwhelming, that when diagnosed, many women are not concerned with the possible physiologic changes or death but rather the psychosocial ramifications that accompany the disease. Stigma then becomes an integral part of the individual experience as much as the biomedical manifestations of the disease (Berger, Ferrans & Langley, 2001; Parker & Aggleton, 2003; Sandelowski, Lambe & Barroso, 2004). The associated fear became the barrier to women achieving the goals necessary for them to maintain and enhance their own health (Carr & Gramling, 2004) and affects women’s reluctance to take medication or attend appointments for fear of being discovered by family and friends who do not know the HIV diagnosis (Fife & Wright, 2000; Hackl, et al., 1997). Stigma continues to be omnipresent in everyday life and is a major source of distress (Ingram & Hutchinson, 2000). Every decision, from taking their medication, attending appointments, and reproductive decision making to caring for their families and maintaining intimate relationships (Ingram & Hutchinson, 1999; Fife & Wright, 2000) is clouded by the undertone of disease-associated stigma. Thus, stigma is a pervasive threat to daily functioning and family management. In order to advance the science it is important to explore how women who are HIV positive and are mothers perceive stigma.

**Self-care Management of HIV**
How individuals manage the long term effects of their own HIV, the demands of the illness, and how they balance illness demands with other individual and family day to day responsibilities influences outcomes (Grey & Sullivan-Bolyai, 1999; Sawyer & Aroni, 2005). Self-care in health has been defined as all activities that individuals undertake with the intention of improving health, preventing disease, limiting the effects of illness, restoring health after illness and injury (Thorne, Nyhlin & Paterson, 2000; Thorne, Paterson & Russell, 2003) and the ability to function on your own behalf. Self-care encompasses the knowledge, attitudes and behaviors that patients develop, nurture or perform to manage a health problem or to enhance a health attribute (Chou, 2004; Chou & Holzemer, 2004). Self-care behaviors are recognized to fluctuate as life and illness present new challenges (Kralik, Koch, Price & Howard, 2004). Self-care includes self-management and self-maintenance (Riegel, 2008). Self-management can be both a structure and a process. Self-management involves problem-solving issues regarding the illness in the context of daily life (Sawyer & Aroni, 2005). Self-maintenance is the cluster of daily behaviors that individual and families perform to routinely manage a condition (Grey, Knafl & McCorkle, 2006).

Studies point to two levels of HIV self-care. One level for self-care for health maintenance (i.e. nutrition, exercise, stress reduction) and a second level specific to managing HIV treatment and care (i.e. symptom management, medication adherence, practicing spiritually based customs such as prayer and engagement with health care) (Coleman, Holzemer, Eller, Corless, Reynolds, Nokes, et al., 2006; Holzemer, et al., 1999; Sowell, et al, 1997). HIV infection is a long-term chronic illness that requires elements of self-care throughout the course of the illness (Anastasio, McMahan, Daniels, Nicholas, & Paul-Simon 1995). The chronic illness literature acknowledges the
importance of self-care and the role it plays in self-management of the illness in HIV positive adults. “Because of the progressive nature of the disease (HIV), much of the necessary primary care is managed in the outpatient setting. As a result, women are responsible for identifying early symptoms or change in health status and communicating this to the health care team. This self-care is tantamount to her health maintenance” (Anastasio, et al., 1995, p. 31). In HIV, there are many physical and psychosocial factors that affect the ability to care for oneself and the physical and psychosocial demands that the illness presents on a daily basis. As a result, people living with HIV disease are challenged to use a variety of self-initiated activities to deal with the physical symptoms and psychological distress from the disease itself and related complex regimens (Chou & Holzemer, 2004 p. 58).

Although few studies have examined gender differences in self-care in HIV disease (Allan, 1990; Sowell, et al., 1997), women may be particularly neglectful of their own self-care. In fact, caring for self was often secondary to caring for family or attending to household needs. Women reported feeling “burdened” by medical treatment, worries about wasting and other symptomatology associated with the disease, attaining resources related to the home and their disease and most of all caring for their children. (Abell, Scott and Kamata, 2006; Anastasio, et al, 1995; Nelms 2005). Additionally, the performance of activities and her perception of her capacity to perform these activities that affect a woman’s self-care are affected by parenting, daily responsibilities, drug use, and social issues related to HIV (Abell, Ryan & Kamata, 2006; Anastasio, et al 1995; Holzemer, et al., 1999; Chou & Holzemer, 2004).

**Self-care and HIV positive parents**

There are substantial role responsibilities and potential stressors associated with
parenting. Being a parent living with HIV, especially a custodial parent, is anticipated to increase psychological distress and challenges to self-care.

There is a paucity of literature regarding self-care in mothers and their children with HIV; the majority of the literature focuses on adults and adherence to medication (Simoni, et al, 2006; Simoni, et al 2005). Only two studies found examined HIV mothers’ self-care behaviors beyond medication adherence; no studies examined self-care behaviors or factors related to self-care in children and adolescents with perinatally acquired HIV. Among the studies identified, the following topics were explored: 1) the processes of engaging in health behaviors and effectiveness of self-management training (Inouye, Flannelly & Flannelly, 2001; Riley, et al, 2001); 2) self-care as women grow older with HIV (Plach, Stevens & Keigher, 2005); 3) self-care management of anxiety and fear in HIV disease (Kemppainen, et al, 2003); and 4) self-care symptom management (Miles, et al., 2001). As previously noted, only one study examined self-care and women who are HIV infected and who cared for a child who is also HIV infected. This pilot study (N=10) used critical ethnography to explore the experiences of self-care practices and cultural meanings of mothering which included self-sacrifice for the care of others (Shambley-Ebron & Boyce, 2006). Traditional self-care behaviors which took the form of following prescribed drug regimens, improving nutritional habits, getting adequate rest, sleep and exercise, and reducing stress were reported to be part of the women’s daily lives but self-care took on different aspects because of culture and complexity of their lives. Further, mothering was inextricably linked to self-care and was a motivation for staying healthy and continuing to live. This limited study highlighted the important differences for women who are HIV-positive and also mothers of a child with HIV and emphasizes the need for further study of this group.

**Chronic Illness in Mother and Child- Context of Childhood Chronic Illness**
**Mother’s role in managing her child’s HIV.** It is universally accepted that mothers play an important role in caring for their children day to day and when that child has an illness, the mother has a key role in managing daily demands as well as the child’s illness. The HIV research literature indicates that HIV-positive women are particularly distressed by demands placed by family and report greater symptoms of distress and substance use than their HIV negative counterparts (Hudson, 2001; Murphy et al, 2002). Despite therapies, which foster easier management of HIV infection, these women continue to experience these demands in ways that may be detrimental to optimal family management.

Traditional family care giving responsibilities of HIV-infected women are often complicated by lack of social support and feelings of grief and loss (Sowell, et al., 1997). Dealing with the feelings that surround management of their own illness often causes them to struggle with the day to day caregiving responsibilities (Hackl, et al 1997). Hackl’s study (1997) showed that primary concerns of women are consistent with those proposed in this study: maternal psychosocial functioning (concerns about death, dying and despair) child concerns (child functioning) and family management (caretaking roles, social support needs). For women living with HIV, the biological impact of the illness has profound personal, social and economic constraints. How they manage their own illness is important to their self-care, potentially to their child’s functioning, and ultimately the outcomes of their child and family.

**Child functioning and parentification.** Parental illness is a stressful experience and poses a potential threat to a child’s physical and mental health and normative development (Pederson & Revenson, 2005). As reviewed in the previous section, physical symptoms for HIV positive persons are a significant burden. When a woman is
a parent, perceptions of fatigue are greater (Lee & Johann-Liang, 1999; Lee &
Rotheram-Borus, 2002). These symptoms affect women’s activities and functional
status, such as their ability care for oneself, to be employed, care for their home and
children and actively participate in their communities (Hudson, et al., 2003). In addition
to the usual tasks of mothering, mothers who are HIV infected and who have children
who are HIV infected have to ensure that their children take appropriate medications and
attend all health care appointments. Mothers care for their children through health crises
and attempt to prepare their children for the future. These responsibilities were arduous,
demanding and stressful (Shambley-Ebron & Boyce, 2006). New challenges have arisen
as HIV infected children survive into adulthood. With this increased life expectancy
comes great responsibility to manage the disease and its associated morbidity to ensure
good quality of life with little effect on physical and mental health (Hazra, Siberry &
Mofenson, 2010).

When both the child and the mother have HIV, it has the potential to change the
family dynamic. “Childhood illness is a specific stressor that can affect psychologic
functioning of all family members particularly if other stressors are present” (Kazak,
1989; Mellins & Erhardt, 2004, p. S 54). A mother who perceives herself as ill may not
be able to adequately take care of her children due to the demands of the illness which
may include emotional distress, substance abuse, and physical symptoms such as
fatigue (Kotchick, et al, 1997). As a result, children may provide substantial amounts of
personal care for their mothers, often taking on personal care tasks, responsibility for
household tasks and some even become their parent’s personal confidante (Bauman,
Foster, Silver, Berman, Gamble & Muchaneta, 2006). This parentification of the child can
lead to poor mother-child relationships which is associated with internalizing and other
problems among children with HIV infected parents (Biggar, et al, 1999; Dutra, et al,
The family perspective on childhood chronic illness. The family plays a pivotal role in the child’s adjustment to chronic illness. When one family member is ill, the entire family is affected (Boiling, 2005). Therefore, individual family members and the family unit are often affected by the presence of a child with a chronic illness (Gallo, Breitmayer, Knaf & Zoeller, 1991). Several studies have examined family perspectives and challenges of caring for a child with chronic illness such as: making sense of illness in terms of life meaning, mastering treatment regimens, adapting to family routines, coping with finances, creating a normal life for the child despite the illness, and negotiating with school and health care professionals (Austin, 1991; Donnelly, 1994; Deatrick, Knaf & Murphy-Moore, 1999; Knaf, Breitmayer, Gallo & Zoeller, 1996; Kurnat & Moore, 1999; Rehm & Franck, 2000; Whyte, 1992). Providing care for a child with chronic illness brings many parents into the rigors of daily responsibility for providing treatment, planning for daily care and visits to the health care provider as well as respite care. The process is time consuming and challenging. Many caregivers in these situations find it difficult to take care of themselves (Boiling, 2005).

Family support, stigma and stress associated with HIV can test even the most intact, well-functioning family. It should not be assumed that the mere presence of family is an indicator of social support (Pequegnat & Bray, 1997). How families perceive and process the sociocultural stressors is an important consideration in how they manage the chronic illness in their daily lives and how they use potential sources of social support including families, friends and professionals.

Family management of children with HIV. Chronic illness is best understood by considering demands imposed by the illness of the entire family and its members. Not
only may a child’s illness affect the family, but also a parent’s illness may affect the
family (Annunziato, Rakotomihamina, Rubacka, 2007). Parents may struggle with their
own illness and their daily care giving responsibilities (Hackl, et al, 1997; Miller, 1992;

Family management describes the family processes that guide illness management
or how family members incorporate care for an ill family member into family life (Knafl,
Deatrick, Gallo, Dixon, Knafl & O’Malley, 2009). The Family Management Style
Framework (FMSF) was originally developed in 1990 by Knafl and Deatrick and has
been periodically refined in a series of empirical and conceptual manuscripts. While their
work has concentrated on childhood chronic illness, other scholars have focused on
other populations (Knafl, Deatrick & Havill, 2012). The framework includes eight
dimensions comprising its three components (Definition of the Situation, Management
Behaviors and Perceived Consequences) (Knafl & Deatrick, 2003; Knafl, Deatrick &
Havill, 2012). The most current conceptual manuscript presents evidence to support the
relevance of the framework and includes the following eight dimensions as comprising
family management: 1) child identity (parents’ view of the child and the extent to which
those view focus on the condition of normalcy and capabilities or vulnerabilities); 2) view
of condition (parental beliefs about the cause, seriousness, predictability and course of
the condition); 3) management mindset (parental views of the ease or difficulty of
carrying out the treatment regimen and their ability to manage effectively) 4) parental
mutuality (parent’s beliefs about the extent to which they have shared or discrepant
views of the child, the illness, their parenting philosophy, and their approach to condition
management); 5) Parenting philosophy (parent’s goals, priorities, values, and beliefs that
guide the overall approach and specific strategies for condition management); 6) management approach (parent’s assessment of the extent to which they and their child
have developed a routine and related strategies for management of the condition and incorporating it into everyday life) 7) Family Focus (parent’s assessment of and satisfaction with how condition management has been incorporated into family life) and 8) future expectation (parent’s assessment of the implications of the condition for their child’s and their family’s future (Knafl, Deatrick, Havill, 2012).

The Family Management Measure (FaMM) is based on the FMSF and was developed through a series of validation studies with parents of children with chronic conditions. An exploratory factor analysis yielded six scales: Child’s Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, Parental Mutuality, and View of Condition Impact. Internal consistency reliability ranged from .72 to .91, and test-retest reliability from .71 to .94. Construct validity was supported by significant correlations in hypothesized directions between FaMM scales and established measures. The current study used three of these factors: ability, effort, and difficulty in managing the child’s condition because these aspects of management were expected to be associated with the child’s outcomes. Understanding how families manage the requirements of illness and family life is an essential for designing effective interventions so that individuals and the family as a whole can achieve better outcomes. Thus, designing research that is sensitive to the health outcomes of HIV-infected children, while being cognizant of the needs of their HIV-infected mothers, is an important step toward realizing positive outcomes for not only children but also their caregivers and families.

There is a dearth of literature about how families who have an HIV positive mother and an HIV positive child manage the treatment of their child’s HIV disease. Chronic childhood conditions impose stressors on family life and a family’s ability to respond to the challenges of managing a child with a chronic condition greatly influences the
subsequent quality of the child’s and family’s life (Santacroce, Deatrick & Ledlie, 2002). One study examined the process through which biological mothers manage their children’s medical treatment. The study found that mothers’ own HIV is interwoven with how they manage related psychosocial issues (Santacroce, et al., 2002). The study found that women were willing to increase the aggressive approaches taken when the mothers’ perception of actual or potential physical, social or psychological harm to her child grew (Santacroce, et al., 2002). More study is needed to understand the relationships among the mother’s perspective about her own illness, decision making on her child’s care, and the child’s health. The demands of raising a child, taken together with the experiences of stigmatization, discrimination, and uncertainty about one’s own future, underscore the needs for health care professionals to better understand the circumstances of HIV positive parents and to develop constructive means of support (Abell, Scott and Kamata, 2006).

**Specific issues to consider the context of HIV.** As noted previously, HIV disease has consequences for the family. Research on HIV and the family is challenging because of the complexities of measurement, the diversity of families across cultures, and the issues specific to HIV affected families including stigma (Pequegnat, et al., 2001). Families affected by HIV differ from families living with some chronic illnesses because mode of child transmission is primarily perinatal and associated with stigma (Rehm & Franck, 2000) and there are disparate numbers of minorities affected by HIV disease (Henry J. Kaiser Family Foundation, 2012). Families with children and parents with HIV are potentially vulnerable because of the likelihood of concurrent infection in the parent and the child, widespread poverty and poor social conditions, disproportionate minority representation, and perceived need for stigma management (Rehm & Franck, 2000).
Gaps in the Literature and Significance of the Study

Although family management models have been used in studies of children with chronic illnesses, more research is needed to test their applicability to HIV disease (Knafl & Deatrick, 2012). Examining how individual factors may be attenuated by family management may provide new information about possible foci for interventions to improve health outcomes in families who experience high demands of caregiving (Bachanas, et al., 2001; Byrne & Honig, 2006; Caliandro & Hughes, 1996; Wrubel et al., 2005).

This study contributes to further understanding of family dynamics and health outcomes in families with a mother and children infected with HIV. The study incorporated the following variables: mother’s quality of life, mother’s self-care, mother’s depression, family management, and mother and child HIV health indicators. Also, the study provides data on key maternal and family management determinants, which potentially affect child outcomes when both the mother and the child have HIV.

In summary, this study allows for the development of the scientific basis for theory-based interventions to assist families cope with pediatric HIV. While HIV infection can be managed, it remains a serious lifelong illness that threatens the health and quality of life of thousands of children and their families in the U.S. In addition, this study may advance understanding of the other chronic conditions that affect both mothers and their children.
CHAPTER 3

Methods

This study sought to understand the relationship between maternal factors, family management and child clinical outcomes in a sample of HIV positive mothers who have a biologically related HIV positive child. In this chapter the study design, study sample, procedures, measures and analysis are discussed.

Research Design

The study used a cross-sectional, quantitative design to explore the relationship between maternal factors, family management, and child clinical outcomes in a sample of HIV positive mothers with a biologically related, HIV positive child with whom they reside and for whom they are the primary caregiver. Sixty-seven mothers and their children were recruited from four outpatient pediatric HIV clinics in the United States. Data were collected through questionnaires and chart review based on the Vincent Model as described in Chapter 1. Data on mother’s quality of life, maternal self-care, maternal depression, family management of the child’s illness, maternal HIV viral load and perception of stigma were collected. Data on the child’s CD4 count and child’s HIV viral load were collected through chart abstraction. Sociodemographic variables to describe the sample were collected using a self-report questionnaire completed by the mother.

Setting and sample. The study population consisted of HIV positive mothers who lived with and were the primary caregivers for their HIV positive children. Children in this sample were 18 years of age or younger. The population was recruited from four Pediatric HIV Clinics in the Northeastern, Southeastern and Midwestern United States. A convenience sample of mothers who attended a clinic visit with their child was
obtained. Mothers who met the inclusion criteria who also had a child meeting the inclusion criteria were invited to participate in the study. Each of the HIV Clinics had research staff members who were experienced in conducting the research under the supervision of an Institutional Review Board (IRB) approved Principal Investigator. Research visits included a consent/assent process, consultation and conduct of the study. Each visit was conducted in a private room with a door for privacy.

**Inclusion and exclusion criteria.** The sample population included all participants who were HIV infected mothers who had at least one biologically related HIV infected child 18 years of age or younger with whom they lived and who they were the primary caregiver. Additional key inclusion criteria were: 1) Maternal age 18 to 60 years of age; 2) ability to read, write and speak English; 3) ability to provide informed consent; 4) ability to participate for the duration of the study which included completion of consent and questionnaires and 5) child able to provide assent when age and developmentally appropriate. Key exclusion criteria were: 1) inability to complete required sociodemographic questionnaires and instruments; 2) not biologically related to the child; 3) unwillingness to allow access to medical records to obtain clinically relevant measures (i.e. child’s CD4 count and percentage and mother and child’s HIV viral load).

**Sample size.** The planned analysis for this study included estimation of sample size. To estimate sample size, an a priori power analysis was conducted. A priori power was assessed for the proposed Model (Figure 1) using two procedures: (1) Kline’s (2005) procedure for estimating samples size in path models and (2) Fritz and MacKinnon’s sample-size procedure to detect mediated, bootstrapped effects. With respect to Kline’s procedure, the path model was complex and included up to 20 parameters: six paths from the predictor to the mediators, six paths from the mediators
to the dependent variable, one path from the predictor to the dependent variable, and seven disturbance terms (one for each mediator and the dependent variable). Kline indicates that statistical precision is maintained in path models when there is a ratio of 10 cases per parameter. Therefore, the path analysis will require 100 subjects: 10 (five predictors, three mediators, and two outcomes) X 10 participants per parameter = 100.

With respect to the Fritz and MacKinnon's, a series of effect sizes were employed. Consequently, to be conservative, a small-to-medium indirect (mediated) effect was postulated. The significance level was set to a two-tailed \( p = .05 \), as per standard scientific conventions. Power was set to .80, meaning there would be an 80% probability of reaching statistical significance if the predictor had an effect in the population. Results from the power analysis showed 148 cases would be necessary. Given the discrepancy between the two estimates, the minimum sample was 100 subjects. In the case of this study, 100 HIV infected mothers Each mother had an HIV infected child which totaled 200 subjects in the study as the model includes analysis accounting for mothers and HIV infected children.

**Instrumentation.** Questionnaires were utilized to collect information regarding the variables of interest in the study; and to achieve the study aims. Each of the questionnaires was IRB approved at the respective participating institutions prior to their use with participants. Questionnaires were completed by the mother. The children in this study did not complete questionnaires. HIV specific clinical laboratory data (i.e. CD4 % and CD4 count and HIV viral load) were collected for the child at the timepoint closest to the study visit within the last three months. HIV specific clinical laboratory data (i.e. HIV viral load) were collected for the mother at the timepoint closest to the study visit within the last year. The instruments utilized to measure the variables of interest in this study are found in Appendix A (Table of Measures). Appendix A further summarizes a brief
overview of the questionnaires with regard to domains and number of items, standardization sample, subject burden, time to administer, and special circumstances (e.g. administration, cost, literacy level using Flesch Kincaid reading grade level). A comprehensive discussion of the standardized instruments used in this study follows.

**Demographics.** Sociodemographic information was collected in questionnaire format by mother’s self-report. All questionnaires were completed using a paper and pencil format. This was not a standardized questionnaire but rather the information collected in this questionnaire was intended to describe the sample. Information obtained from maternal report included gender; age (mother and child); race/ethnicity; marital/partnered status; level of education (mother); current grade of child; religious affiliation; household composition including number of children and HIV status of all household members, if known; identification of who assists mother with managing child’s illness (i.e. giving medication; child care); whether the mother takes daily medications for HIV and/or whether she takes medication for another illness. Clinical data on the mother (CD4 count) and child (CD4 count and HIV viral load) were collected by chart abstraction. In the cases where the mother was not seen in the same clinic as their child, consent to release of records was obtained and information was collected from the clinic where the mother accessed HIV care.

**Maternal Variables**

**Quality of life.** The SF-36 v2 Health Survey® is a well-established quality of life instrument with excellent validity and reliability for the entire scale as well as the subscales. The SF-36 was part of the larger Medical Outcomes Study (MOS) which was a four-year observational study. The goal of the MOS was to develop practical, reliable and valid tools for measuring and monitoring patient-reported functioning and well-being.
for use in clinical and research practice, health policy and general populations (Clayson, et al. 2006; Tarlov, Ware, Greenfield, Nelson, Perrin & Zubkoff, 1989). As a result, a spectrum of patient-reported outcomes included in the MOS SF-36 was created (Shahrier, Delate, Hays & Coons, 2003; Stewart, Hays & Ware, 1988; Tarlov, et al, 1989).

A review of the literature through a Medline (1996-2012) search revealed nearly 8,000 studies referencing the SF-36 and approximately 1% of these also referencing HIV. The usefulness of the SF-36 in estimating disease burden and clinical usefulness has been shown in articles describing more than 130 diseases and conditions (Ware, 2000). The psychometric properties of the MOS SF-36 have been shown to be excellent in many disease areas including HIV/AIDS (Clayson, et al, 2006). Several studies in HIV populations exemplify the measure’s psychometric performance. Samples of these studies are discussed below.

The overall measure has displayed good internal consistency (>0.70 Cronbach’s alpha), reliability (0.68 to 0.93) and responsiveness in a longitudinal, large cohort of HIV positive men (Bing, et.al, 2000). The measure also displayed excellent reliability (.82-.89 Cronbach’s alpha) in a study which examined the influence of symptoms on quality of life among HIV-infected women (Hudson, Kirksey & Holzemer, 2004). Arpinelli, and colleagues (2000) studied a sample of asymptomatic HIV positive adults, both men and women, using the SF-36. In this study, the measure showed internal consistency reliability (>0.70 Cronbach’s alpha). Convergent validity (within scale) was always higher than 0.40. Additionally, the associations between SF-36 health survey scores, Karnofsky scores (well being scale), and CD4 count (a measure of immune status) showed weak to moderate correlation to each other (0.16 to 0.32). These studies represent a broad range of patients affected by HIV and support the psychometric strength of use of this
measure in the population.

The instrument captures the components of physical health and mental health. The SF-36 contains 36 items measured on a 5-level response choice scale. The SF-36 version 2® Health Survey was used for this study. This second version has two component summary scales (physical health and mental health) and eight subscales: physical functioning; role-physical; bodily pain; general health; vitality; social functioning; role-emotional; and mental health; functioning due to physical limitations; general health; role-physical; bodily pain; general health; vitality; social functioning; role-emotional and mental health (Maruish & Turner-Bowker, 2009). Figure 2.1 depicts the SF-36v2® Health Survey Measurement Model. "The Figure is published with permission from OptumInsight Life Sciences, Inc. (f/k/a QualityMetric Incorporated)."
Figure 2.1 SF-36v2® Health Survey Measurement Model

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<tr>
<th>Items</th>
<th>Scales</th>
<th>Component Summary Measures</th>
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<tr>
<td>3a.</td>
<td>Physical Functioning (PF)</td>
<td>Physical Health</td>
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<tr>
<td>3b.</td>
<td>Role-Physical (RP)</td>
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<td>3c.</td>
<td>Bodily Pain (BP)</td>
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<tr>
<td>3d.</td>
<td>Role-Emotional (RE)</td>
<td>Mental Health</td>
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<td>3e.</td>
<td>Vitality (VT)</td>
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<tr>
<td>3f.</td>
<td>Social Functioning (SF)</td>
<td></td>
</tr>
<tr>
<td>3g.</td>
<td>Mental Health (MH)</td>
<td></td>
</tr>
</tbody>
</table>

Note: All health domain scores contribute to the scoring of both the Physical and Mental Component Summary measures. Scales contributing most to the scoring of the summary measures are indicated by a connecting solid line (—). Scales contributing to the scoring of the summary measures to a lesser degree are indicated by a dotted line (—). SF-36®, SF-36v2®, SF-12®, and SF-12v2® are registered trademarks of the Medical Outcomes Trust and are used under license. The SF-36v2® Health Survey is copyrighted (C) 1992, 1996, 2000 by Medical Outcomes Trust and QualityMetric Incorporated.
Table 2 summarizes the component summary measures and health domain scales administered for the SF 36 version 2® Health Survey.

### Table 2 Summary Descriptions of SF-36 Version 2® Health Survey Domains

<table>
<thead>
<tr>
<th>Scale name</th>
<th>Number of items</th>
<th>Summary of what is measured</th>
<th>Score interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Health Component</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Functioning (PF)</td>
<td>10</td>
<td>Measures presence and extent of physical limitation in performing physical activities.</td>
<td>• Low scores indicate significant limitations in performing physical activities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• High scores reflect little or no such limitations.</td>
</tr>
<tr>
<td>Role-Physical (RP)</td>
<td>4</td>
<td>Measures limitations, reductions in the amount of time spent, level of difficulty, and accomplishment of work or daily activities.</td>
<td>• Low scores indicate problems with work or other activities as a result of physical problems.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• High scores indicate little or no problems with work or other daily activities stemming from physical problems.</td>
</tr>
<tr>
<td>Bodily Pain (BP)</td>
<td>2</td>
<td>Measures intensity of pain and extent of interference with normal activities due to pain.</td>
<td>• Low scores indicate high levels of pain that impact normal activities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• High scores indicate no pain and no related impact on normal activities.</td>
</tr>
<tr>
<td>General Health (GH)</td>
<td>5</td>
<td>Measures of rating of health (excellent to poor). Measures respondent’s views and expectations of her health.</td>
<td>• Low scores indicate evaluation of general health as poor and likely to get worse.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• High scores indicate that the respondent evaluates his or her health most favorably.</td>
</tr>
</tbody>
</table>

**Mental Health Component**

53
<table>
<thead>
<tr>
<th>Measure</th>
<th>Item</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitality (VT)</td>
<td>4</td>
<td>Measures vitality (i.e. fatigue and energy level).</td>
<td>Low scores indicate evaluation of feelings of tiredness and being worn out.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>High scores indicate feeling full of energy all or most of the time.</td>
</tr>
<tr>
<td>Social Functioning (SF)</td>
<td>2</td>
<td>Measures health related effects on quality and quantity of social activities. Specifically asks about the impact of physical or emotional problems on social activities.</td>
<td>The lowest scores equate to extreme or frequent interference with normal social activities due to physical and emotional problems.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>High scores indicate that the individual performs normal social activities without interference from physical or emotional problems.</td>
</tr>
<tr>
<td>Role-Emotional (RE)</td>
<td>3</td>
<td>Measures mental health-related role limitations in terms of time spent doing work or other usual activities; amount of work accomplished and the care with which work or other activities were performed.</td>
<td>Low scores on this scale reflect problems with work or other activities as a result of emotional problems.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>High scores reflect no limitations with work or other activities as a result of emotional problems.</td>
</tr>
<tr>
<td>Mental Health (MH)</td>
<td>5</td>
<td>Measures four mental health dimensions: anxiety, depression, loss of behavioral /emotional control and psychological well-being).</td>
<td>Low scores indicate frequent feelings of nervousness and depression.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>High scores indicate feelings of peace, happiness or calm all or most of the time.</td>
</tr>
</tbody>
</table>

As outlined in table 2, there are eight subscales. Scores are reported for each of the eight subscales and two composite scores based on the subscales (physical health and mental health). The scale takes approximately 5-10 minutes to complete. The measure uses a 4 week recall format. Scores are calculated using an overall sum score and subscale scores on the physical and mental health domains. Scores used for this instrument are T scores (formerly referred to as “norm-based scores”). This norm based scoring employs a linear T-score transformation where mean = 50 and standard deviation = 10. This makes it possible to meaningfully compare scores for the eight-scale profile and the physical and mental summary measures (Kosinski, Bayliss, Bjorner, & Ware, 2000). Higher scores on the measure indicate a higher perception of good quality of life. Lower scores indicate poor quality of life. The eight subscales were used in analysis of this study to capture the multidimensional nature of quality of life.

**Self-care.** The Parental Self Care Scale (Abell, Ryan & Kamata, 2006) is a measure of a woman’s perception of her capacity for self-care in the context of having parenting and household responsibilities. The measure was developed and tested with a culturally diverse population in the United States. The PSCS is a 20-item scale with an overall global score and three subscales (emotional, instrumental and nursing). Regarding content validity, all items in the original PSCS pool received mean ratings greater than 3.0 (M=3.79, SD=.90) with 80% greater than 3.5 indicating “quite a bit” of fit between item content and construct definition. Internal consistency reliability estimates were > .70. The measure demonstrated equivalence across language groups. The measure showed good initial indications of construct validity (Abell, et al., 2006). Although the
measure has not been used as extensively as others, the measure was developed using strong conceptual underpinnings of self-efficacy and self-management. The measure captures the perception of capacity for self-care in the context of caring for others in the family and its composition most closely matches the conceptual definition of self-care for the proposed study. This measure is a 20-item scale with an overall global score and three subscales (emotional, instrumental and nursing) measured on a 10-point Likert scale. The overall global score will be used in analysis for this study. The measure takes 5-10 minutes to complete. Higher scores indicate higher capacity for self-care.

**Depression.** The widely used Center for Epidemiologic Studies-Depression (CES-D 20) is a self-report depression inventory which captures information on depressive symptoms over the past week. The CES-D measures six components of depressive symptoms: depressed mood, feeling of guilt and worthlessness, feeling of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. Participants rate each of the 20 items on a 4 point scale, ranging from 0 (rarely) to 3 (frequently). A score on this instrument can range from 0-60. Higher scores indicated more depressive symptoms and a score of 16 or greater might indicate risk for depression (CES-D) (Radloff, 1977). The CES-D has demonstrated construct (convergent) validity by significant correlations with the Hamilton Depression Scale (0.56) and the Beck Depression Inventory (0.81). Several studies measuring depressive symptoms among the population of women and mothers with HIV have obtained strong internal consistency with Cronbach alpha coefficients ranging from .84 to .92 (Catz, Gore-Felton & McClure, 2002; Hudson, et al., 2003; Miles, et al., 2001; Miles, Holditch-Davis, Eron, Pederson & Harris, 2003).

The measure takes approximately 10 minutes to complete. Scale scores range from 0 to 60 with higher scores indicating greater risk for depressive symptomatology.
**Stigma.** Berger Stigma Scale is a self-report inventory, which includes 40 items rated on a 5-point scale from “Strongly Disagree” to “Strongly Agree”. An exploratory factor analysis, at the time of subscale development, using a common factor method of alpha extraction resulted in 4 factors defined as the following subscales: 1) Personalized Stigma: consequences of other people knowing their status; 2) Disclosure Concerns; 3) Negative Self Image: not as good as others, shame, guilt; and 4) Public Attitudes: what people think about HIV. The scale demonstrates good internal consistency (coefficient alphas range between .90 and .93 for the subscales and .96 for the 40-item instrument).

Construct validity was assessed by examining the relationship between 5 scales, which examined self-esteem, depression, social support, social integration and social conflict. Results supported the scale and included moderate negative correlations of the 5 scales with the total stigma score and with personalized stigma, negative self-image, and concern with public attitudes subscales. There were slightly weaker negative correlations with the disclosure subscale (-.68 to -.35). Social conflict was positively related to the total stigma scores and all subscores (.40 to .59). The measure takes 10-15 minutes to complete. The range of possible scores depends on the number of items in the scale. For the total HIV Stigma Scale, scores can range from 40 to 160 [1 x 40 items to 4 x 40 items]. For the personalized stigma subscale, scores can range from 18 to 72. For the disclosure subscale, scores can range from 10 to 40. For the negative self-image subscale, scores can range from 13 to 52. For the public attitudes subscale, scores can range from 20 to 80. Higher ratings indicate greater perception of stigma (Berger, et al, 2001) and correlated with greater depressive symptomatology. Results from the Berger stigma instrument are discussed in more detail in Chapter 4.

**Mediator Variables**
Family Management of the child’s illness was measured using the Family Management Measure (FaMM). The FaMM is a psychometrically sound, 53 item measure with 45 items for all parents and eight additional items for partnered parents only. Items are scored from one to five, meaning “strongly disagree” to “strongly agree”. There are five summated scales for all parents measuring the dimensions of Child’s Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, and View of Condition Impact as well as a sixth scale only for partnered parents measuring the dimension of Parental Mutuality. Higher scores on three of the scales (Child’s Daily Life, Condition Management Ability, Parental Mutuality) indicate greater ease in managing the child’s condition. Higher scores on the other three scales (Condition Management Effort, Family Life Difficulty, and View of Condition Impact) indicate greater difficulty in managing the condition (Family Management Measure, 2009). Internal consistency reliability ranges from .72-.91 and test-retest reliability from .71-.94. Three of the subscales were used in this study: Condition Management Ability, Family Life Difficulty and Condition Management Effort showed internal consistency reliability of .72, .90 and .74 for mothers respectively (Knafl et al, 2009). The rationale for choosing these three subscales was because the three scales most closely represent the aspects of the mother’s perception of effort, difficulty and her ability in managing this condition. For HIV disease these aspects of disease management are important because as noted above, in most cases, management of HIV requires daily medications for both the mother and the child which can add to the daily demands placed on the family and in particular the mother as caregiver. These subscales will provide a picture of how mothers perceive the effort and difficulty of having an HIV infected child as well as their ability in managing her child’s disease.

Construct validity showed significant correlations in hypothesized directions between
FaMM scales and the established measures. “These results demonstrate support for the construct validity of the six FaMM scales through a consistent pattern of significant relationships in hypothesized directions between the scales and established measures of child and family functioning” (Knafl, et al., 2011). Negative relationships were found between the General Functioning Scale of the FAD (with higher scores indicating poorer functioning) and Condition Management Ability and positive relationships between the FAD and Condition Management Effort and Family Life Difficulty. The positive associations between the FAD and the Condition Management Effort and Family Life Difficulty indicated that parents who viewed the child’s condition as more serious, who believed family life was more difficult because of the condition, and who experienced condition management as requiring considerable effort had more negative perceptions of their family’s functioning. Parents’ perceptions of the child’s functioning also were significantly related to the FaMM scales in the predicted directions. Both the Intensity and Problem scales of the Eyberg Child Behavior Inventory (ECBI) were negatively associated with Condition Management Ability and positively associated with Condition Management Effort and Family Life Difficulty, indicating that parents’ perceptions of the relative ease or difficulty of condition management were linked to their perceptions of problematic behaviors in their child. Parents who viewed their child as having more problematic behaviors also were more likely to view the child having a less normal life as a result of the condition. The relationship between the FSM II and the FaMM also was as expected, with better child functioning significantly positively associated with Condition Management Ability and significantly negatively associated with Condition Management Effort, and Family Life Difficulty (Knafl, et al., 2009).

For the three subscales used (condition management ability; condition management effort and family life difficulty) there are 30 items, which take approximately 15 minutes
to complete. Higher scores on these subscales indicate greater difficulty managing the child’s condition.

**Outcome Variables: CD4 Count and HIV Viral Load**

Absolute CD4 count (and CD4 percentage) and HIV viral load are the two laboratory measures used to determine clinical health status for the child and are the outcome measures in the Vincent Model. HIV viral load is also measured for the mother and is an independent variable in the Vincent Model.

For this study, the last available CD4 count and HIV viral load closest to the study visit were abstracted from the mother and child’s chart or obtained through a release of records request. CD4 count and HIV viral load are two laboratory measures (surrogate markers) which help health care providers monitor progression of HIV disease. The CD4 cell is a type of white blood cell, that fights infection. HIV enters CD4 cells and replicates which leads to a gradual decline in CD4 cells resulting in damage to the immune system. The resultant immune suppression, especially if severe, predisposes the individual to HIV disease progression (DHHS 2009; DHHS 2011).

HIV viral load is a quantitative measure of how much HIV is in the bloodstream (HIV viremia). A detectable viral load indicates that the virus is reproducing in the body, which leads to disease progression. An undetectable viral load does not mean that the virus is not present but rather is an indication that the virus is suppressed in the body usually due to treatment with highly active antiretroviral therapy (HAART). Additionally, HIV viral load has long been established as a prognostic marker and CD4 has been established as the most significant predictor of disease progression and survival. It is known that there is a relationship between HIV viral load and CD4 count (CASCADE, 2004; Langford, Ananworanich & Cooper, 2007; Phillips & Lundgren, 2006). In general, if
the HIV viral load is high, the CD4 count is generally low. This inverse relationship of low CD4 count reflecting immune suppression and detectable viral load is accepted in managing HIV.

The standard of health care metric for adult HIV specialty care is a visit to a HIV specialty health care provider and lab work every 6 months. Mother’s HIV viral load was included in the analysis if the mother was seen by her HIV provider in the past year. The time point of clinical laboratory data were collected closest to the study visit. The standard of care metric for the child is every three months. Child’s CD4 count and HIV viral load were included in the analysis if the child was seen within the last three months and the time point of clinical laboratory data was collected closest to the study visit (DHHS 2008; DHHS, 2010). The CD4 count and percentage, a reflection of immune status, was coded per the CDC Classification. For children under the age of 13 years, the CDC classification appropriate for this age group was used (refer to Appendix B). The child’s CD4 count were coded as mild, moderate or severely immunosuppressed using the age appropriate CDC guidelines (CDC, 2012d; CDC, 2012e). The HIV viral load, an indicator of viral control, was dichotomized into two groups undetectable and detectable for both groups. An undetectable result indicates that the person has good viral control and a detectable result indicates that there was presence of virus, which indicated poor viral control (DHHS, 2008; DHHS, 2010).

**Potential Covariates**

The inclusion of covariates in this study provides a comprehensive examination of potential confounders that may explain relationships that may influence independent and dependent variables. Based on the HIV and chronic illness literature pertaining to women and children, the following three covariates were chosen for inclusion in the
analysis plan for this study: 1) whether the parent has assistance in managing her child/children within the home (i.e. a live-in spouse, partner, family member or friend); 2) HIV disclosure status; and 3) whether the mother takes medication for HIV.

The mere presence of parental physical illness can create relationship conflicts. In these cases, knowing the constellation of a family and identifying whom the mother identifies as helping in the household with children and household chores is important for family outcomes (Armistead, Klein and Forehand, 1995; Pequegnat, et al, 2001). Additionally, when a parent, in this case the mother, takes medication, it adds the potential complication of an additional care burden within the household. Another prevalent aspect to consider in HIV is HIV disclosure status, particularly if the mother has disclosed her status to her child and other household members. Of significance is that disclosure had a reported impact not only on their own life but that of the child (Armistead, et al, 1995; Moneyham, et al., 2000; Murphy 2008; Tompkins, et. al, 1999). The information regarding the three potential covariates (i.e. who assists the mother in caring for her HIV infected child; whether the mother takes medication for HIV; whether the mother has disclosed her HIV infection status to her HIV infected child) considered in this analysis was collected through self-report on a sociodemographic questionnaire.

**Study Procedures**

**Recruitment, screening and consent/assent.** The study sample was recruited over a period of 16 months from four pediatric HIV clinics in the United States as identified earlier. Each clinical research site obtained IRB approval prior to conducting the study. Each clinical research site was chosen because of their willingness to participate and each site had over two decades of experience in conducting clinical research in HIV populations. Each site had a Principal Investigator (PI) who was...
responsible for the conduct of the research study at the site. The PI and designated research staff met with the lead investigator in person or by phone for a start up meeting to review procedures for the conduct of the study. Additional correspondence was conducted by phone or secure electronic mail correspondence and use of secure File Transfer Programs (FTP). The research staff at each site worked with clinicians and social workers to identify potentially eligible mother child dyads. Due to the sensitive nature of HIV, no posters were placed in the clinic area since many families attend clinic visits with family members or friends who do not know their HIV diagnosis. Once identified, the research staff approached the potential participants for the consent/assent process. The IRB approved verbal consent/assent process took place prior to data collection. All consent and assent discussions were held in a private room with a door to minimize the prospect of accidental disclosure of the HIV diagnoses and participation in a study. Only the mother was present for the consent process to further minimize accidental disclosure. The HIV positive child was approached after the mother consented to participation in the study. If the child was at the age of assent and knew his/her HIV diagnosis, the child was approached for assent for use of his/her clinical laboratory data. The child was approached for consent if he/she had reached 18 years of age. If the child agreed to participation, clinical laboratory measures (CD4 count and percentage and HIV viral load) were collected through chart abstraction. The mother provided sociodemographic information on the child to minimize child subject burden.

**Data collection.** Sociodemographic characteristics collected in this study included gender; age of mother; age of child; marital status; race and ethnicity (self-reported), years of education; employment; level of income; religious preference; housing; and number of persons living with the mother. Additional information were also gathered
regarding each person living with the mother. This information included how each person was related; HIV status of each person; disclosure of HIV status of the mother within the household; whether each person takes medication; and whether the mother had help giving her child medication. Clinical information was collected from chart review or through information received from the HIV specialty provider caring for the participant after obtaining proper release of records consent. Clinical and/or research staff were informed of the study including purpose, methods of data collection and review of importance of assessing participants for safety due to the sensitive nature of the questionnaires. Patients who met all inclusion criteria for the study and had no exclusionary criteria were identified by the research staff and were recruited for the study. Potential participants were first asked if they would like to learn more about the study. If they showed interest, the patient was referred to the investigator or the research staff at the respective participating institution. In all cases, the potential participants were given the option to decline participation and reasons for non-participation were collected and are presented in chapter 4.

To avoid coercion to participate, if the investigator was known to the subject, another member of the research staff was enlisted to assist in conducting the study visit. In an attempt to decrease subject burden, participants were given the option to complete the study at the time of their child’s or their own clinical visit or at a mutually convenient time. Participants were asked to complete the questionnaires in a comfortable setting where there would be privacy and little chance of interruption. Participants were asked to complete the questionnaires and if they had questions, a research staff member was available to assist them. At the completion of the questionnaires, a research staff member reviewed the questionnaire for missing items. If missing items were identified, the participant was asked to complete them if possible. Each participant was asked to
stay while the questionnaire was reviewed for completeness and each participant was
de-briefed to ask questions and ensure that the study did not evoke emotion in such a
way that the subject would want to harm herself or others. Participants were given the
option to withdraw from the study at any time for any reason. Participants were given the
name and contact information of the lead investigator in order to allow the participants to
ask questions or access study results after the completion of the study.

Each participant was given a questionnaire packet, which contained seven
questionnaires that took approximately 50 minutes to complete. As noted, missing
questionnaire items were minimized through review of the questionnaires by a research
staff member. There were less than 1% of missing items on questionnaires and none of
the missing items affected scoring of the instruments. In the event of missing data that
would have affected the scoring, the design of the study accounted for imputation
methods to maximize ability to use the data. This included instrument specific scoring,
for example. No imputation was required for scoring in this study.

Data Management and Data Analysis

Each of the mothers and their children were given a unique patient identifying code.
All Protected Health Information (PHI), and patient identifying code linking the subject
name to the data for this study were not entered into the database. These data were
stored in a password protected database or on a paper chart which was stored in a
locked filing cabinet in a locked office accessible only to IRB approved study staff. This
information was maintained at each respective participating site. The information was
maintained to ensure that potential subject’s were not included more than once. All
participant completed paper questionnaires were stored in a locked filing cabinet in a
locked office behind a locked office door accessible only to IRB approved study staff.
There was one IRB approved Data Coordinating Center (DCC) for all of the recruitment sites. All patient questionnaires were sent via secure File Transfer Programs to the DCC for entry into a password protected database. All paper records and electronic data were kept and stored at the respective institutions according to the Institutional policies for research record retention. A database was built and maintained using REDCap™. Study data were collected and managed using REDCap™ electronic data capture tools hosted at the DCC. REDCap™ (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources (Harris, Taylor, Thielke, Payne, Gonzalez & Conde, 2009). Data cleaning was performed after each entry to ensure accuracy and to check for missing data. The lead investigator reviewed all records, calculated all scores, reviewed calculations against database calculations for accuracy and assured valid entries.

Data analysis. Data analysis was driven by the specific aims and study hypotheses based on the Vincent Model (Figure 1). All quantitative results were scored, analyzed and entered into a password-protected database (REDCap™). Data were exported to SPSS for Windows to start the analysis. Data were summarized using descriptive statistics. Measures of central tendencies (mean, median, mode range and standard deviation) were calculated for all continuous variables. Frequencies and percentages were calculated for categorical values. Quantitative analysis continued with univariate analysis, linear, multivariate regression analysis (MRA) and logistic regression models, ANOVA and Pearson r correlations.
**Analysis by aim.** Covariates were analyzed using univariate analysis (single order linear relationship analysis). Pearson’s $r$ correlation among the measures was calculated. If a strong correlation did not exist between the co-variable and the dependent variable, the covariate measure was excluded. A strong correlation was defined as $R^2 \geq 0.60$ (Allison, 1999). None of the covariates, as described in Chapter 3, were significantly related to the overall Model. Thus, none of the covariates were incorporated in the Model for further analysis.

**Specific Aim 1.** The first specific aim examined the relationship between maternal factors and family management of the child’s illness factors (ability, management, effort). Measures of central tendency were used to describe each of the variables (means, standard deviations). A series of direct-entry multiple regression analyses were performed. The influence of each variable was examined for directionality, strength and statistical significance.

**Specific Aim 2.** The second specific aim examined the relationship between maternal factors and child clinical outcomes. Binary logistic regression analyses were performed to explore this aim.

**Specific Aim 3.** The third specific aim examined the relationship between family management of the child’s illness factors (ability, management, effort) and child clinical outcomes. Binary logistic regression analyses were performed to explore this aim.

**Specific Aim 4.** The fourth specific aim explored whether family management of the child’s illness factors (ability, management and effort) functioned as a mediator between maternal factors and child clinical outcomes. To test this, a series of regression models were employed using Preacher and Hayes (2008) mediation methodology. A thorough explanation of the findings for all aims using these analytic techniques follows in Chapter 4.
**Secondary Aim.** A secondary aim sought to describe maternal perception of stigma regarding: concerns about consequences of others knowing their HIV status; concerns about disclosure; self-image and public perception of HIV. Each maternal participant completed the Berger Stigma Scale. The scale was scored for each participant and a discussion of the scores and interpretation will follow in Chapter 4.

**Human Subjects Considerations**

**Potential risks and benefits.** The study was reviewed and IRB approved under the risk/benefit determinations as described in the Code of Federal Regulations (CFR) 45, Part 46 Subpart D as research not involving greater than minimal risk (HHS, 2012). The study employed questionnaires, which may have elicited emotion related to difficult questions related to HIV and management of disease. To further protect participants in this study, a safety plan was incorporated at each site to minimize undue stress. At each site, a safety plan included ensuring the participants were given the opportunity to ask questions, were de-briefed to assess for intention to hurt self or others after answering survey questionnaires, and the opportunity to discontinue study participation as needed. Study participants who expressed emotional concern were referred immediately to the clinic designated mental health professional or Emergency Department for evaluation. All participants were monitored for fatigue, undue stress or distress. All staff were trained to evaluate participants for such issues as part of the overall safety plan. To maximize retention for the one time questionnaire, subjects were given the opportunity to take breaks, return within a few days if necessary or opt out of the study if necessary. Participants were also reminded that if they chose to discontinue participation, the decision would not affect their care or their child’s care at the respective institution. With the exception of two cases, the study questionnaires were completed in one session.
One participant had to pick up a child from school. She returned the next morning to complete the questionnaires. A second participant became overwhelmed with emotion when completing the stigma questionnaire. This participant was assessed, as per the safety plan, and deemed stable enough to leave clinic with follow up by the clinic staff. At her request, she was able to complete the questionnaire at a later time. She was assessed by a clinic mental health professional before and after returning to ensure she was stable to complete the information.

Subjects were advised of their right to disclose their own HIV status and their right to disclose participation in the study to personnel providing care outside of the study, as in the case of a referral to an emergency department or outside psychologist. The study staff (principal investigator and research staff) are not at liberty to disclose this information without the subject’s permission. The study measures were chosen to limit subject burden and took approximately 50 minutes or less to complete. From the beginning development of the study, all procedures were chosen to minimize participant risk and limit participant burden while maintaining scientific integrity of the study. Subjects were compensated per IRB guidelines for time and effort related to study participation. Study subjects were assured that the information, including demographic information, survey questions and chart abstraction data for the study was collected for the purposes of research, and were kept confidential and were not accessible to anyone outside of the study research team. Names were not linked to the raw data nor to the data once cleaned and entered into the database. All participants were advised of this information.

**Potential benefits of the proposed research to subjects.** There was no direct benefit to study subjects. Information gained from the study may help future families affected by HIV and chronic illness. The results of this study may have important
implications to healthcare providers and researchers developing interventions, which improve outcomes for the child and potentially the family.

**Inclusion of women, children, and minorities.** Inclusion of women and children is scientifically justified due to the need to identify issues related to family and self-management in women and their children with HIV. Thus, both women and children are included as they are the focus of this study. The study included minorities and is reflective of the population of the clinics which participated in the study. It is also reflective of the demographic of HIV in the United States (CDC, 2012).
CHAPTER 4

Results

The purpose of this study was to describe families who have both a mother and a child living with HIV. The study describes and examines factors which may predict children’s health outcomes when they and their mothers are HIV infected and considers the potential for mediation of this relationship by the family management of the child’s illness factors: condition management ability, condition management effort and family life difficulty. The results of this cross-sectional, quantitative study are reported in this chapter. Sample characteristics are described and descriptive findings (n, means and standard deviations) on the measures of key variables from the Vincent Model (Figure 1) are presented. The quantitative analysis results from each specific aim are provided. There are four specific aims. For each of these aims, hypotheses were tested through use of quantitative methods: descriptive statistics; univariate analyses to test each variable for directionality, strength and statistical significance; linear, MRA and binary logistic regression analyses; Pearson’s r, t-tests and Analysis of Variance (ANOVA); and mediation analyses including bootstrapping. Results of these analyses are reported here.

Sample

A total of 67 HIV infected mothers and their HIV infected children participants were recruited from four HIV specialty outpatient clinics in the United States. The majority of the participants were recruited from the Mid-Atlantic sites (n= 39); followed by Mid-South (n=22); and Midwest (n=6). The majority of the sample data are directly related to questionnaires completed by the mother. Thus, descriptive data reported here is
primarily reported for the mother. When reporting maternal data, the word mothers will be used. Descriptive data for the child is indicated when appropriate. When reporting child data, child participant will be used.

**Maternal Demographic characteristics**

All mothers in the study were female (n=67; 100%). Mothers ranged in age from 23 to 53 years (mean of 37.06 years). The majority of mothers reported their race as African American/Black (n=53; 79.1 %) and non Hispanic/Latina (64; 95.5%). The majority of mothers were never married (n=32; 47.8%) and did not live with a partner or spouse (59; 88.1%). Mother’s income was self reported less than $15,000 (n=45; 67.2%). The majority lived in their own home/apartment (n=59; 88.1%). Mothers reported that their household size (not including herself) ranged from 1-7 persons with a mean of 3.37. Many mothers completed some college (n=21; 31.3%) and work outside the home (n=34; 50.7%). Religious preference was reported as primarily Christian (Protestant and Catholic combined) (n=45; 67.2%). The mean number of years since maternal HIV diagnosis was 11.09 years. The number of years since HIV diagnosis statistic was only available for 65 of the 67 mothers. The mean age of the HIV infected child in this study was 10.22 years (range 1 year to 18 years). Table 4.1 presents demographic characteristics of the study participants.
Table 4.1
Demographic Characteristics of Study Participants* (Mothers unless indicated)

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* Mothers unless indicated.

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Description of Recruitment Sites

The study sample and subsequent data for this study were obtained through four study recruitment sites in the continental United States. Each clinic provides health care and psychosocial services for perinatally HIV infected children and adolescents. All eligible patients were approached for participation in the study. During the recruitment period, an additional 32 patients were eligible for study but declined participation. Reasons given were as follows: English read and spoken but as a second language (n=5); too busy (n=5); afraid of disclosure (n=4); do not participate in any studies (n=4); child aged out of study (n=4); mother deceased or disabled (n=2); change in legal guardian status (n=2); mother not present at visits/not available (n=2); too many other medical appointments (n=2); lived too far away from clinic to stay additional time for study (n=1); and mother too ill to participate (n=1).

Measures

Means and standard deviations for maternal and family management variables are presented in Table 4.2. Summary descriptive statistics are provided for each of the measures for the variables of interest.
Table 4.2

*Means and Standard Deviations for Family Management Factors and Maternal Factors*

<table>
<thead>
<tr>
<th>Variable</th>
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<td>Role-Physical</td>
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<tr>
<td>Bodily Pain</td>
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<td>11.73</td>
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<td>1.92</td>
</tr>
<tr>
<td>Depression</td>
<td>19.97</td>
<td>13.23</td>
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*Note: $M =$ mean, $SD =$ standard deviation, $N = 67$. Numbers rounded at second decimal point for convenient presentation.*
Quality of life. Maternal Quality of Life was measured using the SF-36 v2® Health Survey. Items were scored using the measures licensed software and data was transformed into the study database and exported to SPSS. The sample data from the eight domain subscales are described below. Norm based T scores for the measure were used with mean= 50 and standard deviation=10. This measure also includes a Response Consistency Index (RCI) score, which evaluates the consistency of responses to individual survey items. The best, most consistent, score is 0. Further, if at least 90% of the individual respondents have a score of zero, the data quality is considered satisfactory (Mariush & Turner-Bowlek, 1999). In this sample, scores ranges from 0-4, with a mean of .30 and standard deviation of .80. The overall percentage of individuals with a score of zero was 92.5%, which indicates good consistency of responses. Overall, mothers reported that their health was about the same as in the previous year (n=33; 49.3%).

Physical functioning. Physical functioning indicates the extent to which physical limitation in performing physical activity was present. Scores ranged from 14.94 to 57.03. The mean was 47.11 and the standard deviation was 11.43. Overall, mothers reported that they were limited with vigorous activities such as running or lifting heavier objects (n=40; 59.7%); and climbing several flights of stairs (n=35; 52.2%), but not limited in everyday activities such as lifting and carrying groceries (n=52; 77.6%), walking short distances (n=48; 71.6%); and bathing or dressing (n=63; 94%).

Role-Physical. Role-Physical measured limitations and reductions in the amount of time spent, level of difficulty, and what the mothers perceived they accomplished in their work or daily activities. Scores ranged from 17 to 85. The mean was 46.11 and standard deviation was 11.39. Over half of the mothers reported that they had some degree of
limitation in the kind of work or activities little to all of the time (n=35; 52.2%); and they reported that they accomplished less than they would have wanted to in their work or daily activities (N=43; 67%). Most did not cut down the time spent on work or other activities and did not report difficulty in the performance of work or other activities (for both n=34; 50.7%).

**Bodily pain.** Bodily Pain measured the intensity of pain and the extent of interference with normal activities due to pain. Scores ranged from 19.86-62.12. The mean was 45.20 and standard deviation was 11.73. The majority of mothers reported that they had pain ranging from mild to very severe over the past four weeks (n=53; 79.1%). A small percentage of mothers (n=14; 20.8%) reported no pain. Pain interfered with normal work inside and outside the home in 67% of the mothers (n=45; 67.1%).

**General health.** General Health indicated the mother’s rating of her own health as well as views and expectations of her health. Scores ranged from 18.61 to 63.9. The mean was 45 and the standard deviation 11.35. Mothers reported good general health (n=21; 31.3%). Just over half believed that they did not get sick more easily than other people (n=34; 50.8%). Nearly one-third of mothers reported uncertainty (don’t know) in whether they expected their health to get worse (n=21; 31.3%).

**Vitality.** Vitality measured the woman’s rating of fatigue and energy level. Scores ranged from 20.87-70.82. The mean was 48.59 and the SD was 11.14. The mothers in this sample reported having a full life most or all of the time (n=35; 52.2%). Mothers reported that they had low energy levels, reporting that some of the time (n=20; 29.9%), a little of the time (n=14; 20.9%) and none of the time (n=5; 7.5%) they did not have a lot of energy. Also, most mothers felt worn out at least some of the time (n=40; 59.7%) and notably reported fatigue at least some of the time (n=50; 74.6%).

**Social functioning.** Social Functioning indicated health related effects on quality and
quantity of social activities. This measure also indicated the influence of physical and emotional problems on social activities. Scores ranged from 13.22 to 56.85. The mean was 43.74 and the standard deviation was 11.32. Overall, mothers reported that their physical health and emotional problems interfered only slightly or not at all with social activities (n=47; 70.1%). Physical health and emotional problems only interfered with social activities some of the time (n=18; 26.9%) to little or none of the time (n=39; 58.2%).

**Role-emotional.** Role-emotional measured health related role-limitations in terms of time spent doing work or other usual activities, the amount of work accomplished and the care with which work and other activities were performed. Scores ranged from 9.23 to 55.88. The mean was 42.88 and the standard deviation was 13.78. Just over half (n=34; 50.7%) of the mothers reported that they did not cut down on the amount of time spent on work or other activities. Most reported that they accomplished less than they would have liked (n=38; 56.7%) and many reported that they did work or other activities less carefully than usual (n=34; 50.7%).

**Mental health.** Overall, Mental Health (MH) measured four mental health dimensions: anxiety, depression, loss of behavioral/emotional control, or psychological well-being. A MH score of 37 is the measure cutoff for detecting depression (Ware, Kosinski, Bjorner, Turner-Bowlek, Gandek & Mariush, 2007). Scores on the mental health scale ranged from 16.22 to 64.09. The mean was 43.83 and the standard deviation 13.33. Fifty six mothers (83.5%) reported scores of 37 or higher indicating risk for depression. Overall, mothers reported feeling nervous ranging from a little of the time to all of the time (n=48; 71.6%). 58% reported that they felt so ‘down in the dumps nothing could cheer them up’. This ranged from a little of the time (n=11; 16.4%) to some of the time (n=19; 28.4%); to most or all of the time (n=9; 13.5%). Conversely, when
asked if they felt calm and peaceful, the majority of mothers noted they felt this way some to all of the time (n=53; 79.1%). When mothers were asked if they felt downhearted and depressed, the majority reported feeling this way a least a little or some of the time (n=29; 43%) to most or all of the time (n=14; 20.8%). When asked if they felt happy, mothers noted that they did feel happy some, most or all of the time (n=57; 85%).

Self-care. Maternal capacity for self-care was measured using the Parental Self Care Scale (PSCS). The scale score was 1-10. A higher total indicated the mother perceived she had a higher capacity for self-care. Cronbach’s alpha was .95. The sample scores ranged from 2.65 to 10 (mean= 8.01; SD=1.92). The majority of mothers reported scores of 6 or higher, which indicates they perceive that they have capacity for self-care in the context of their daily life (n=64; 86%).

Depression. Maternal depression was measured using the CES-D 20. Items were summed to yield a total score. Scores for the measure range from 0-60 with scores 16 or greater indicating a higher risk for depression. The sample scores ranged from 0-51 (mean=19.97; SD=13.23). Cronbach’s alpha was .93. The majority of mothers (n=35; 52%) reported scores of 16 or greater indicating a higher risk for depression. One item in particular in the CES-D, whether the woman could not “shake off the blues” even with help from her family, showed that mothers felt they could not do this 75% of the time. This supports the finding in the mental health scale of the SF 36 v2® “where mothers felt so down in the dumps that nothing could cheer them up”. On the mental health scale of the SF 36 v2, mothers obtained scores consistent with depression cutoffs over 83.5% of the time. Thus, the results from the CES-D are consist with scores on the mental health component of the SF 36 v2 indicating risk for depression in this sample.

Maternal clinical data (CD4 count and HIV viral load). Maternal HIV clinical
measures (CD4 count and HIV viral load) were collected for the last visit within one year of the study visit as noted in chapter 3. In HIV disease, the CD4 count declines due to the presence of an elevated HIV viral load since the HIV virus directly attacks CD4 cells. In the Vincent Model (Figure 1), maternal CD4 and HIV viral load were both specified as measures, which were hypothesized to affect child outcome. However, since they are part of the same causal pathway, only one was included in the Model. Viral load is a more proximate measure of clinical status and therefore was chosen over CD4 for inclusion in the Model.

The HIV viral load in this sample was dichotomized into detectable and undetectable. Thirteen of sixty seven mothers had not had a health care visit for HIV management in the past year. Since none of these mothers were on HIV medications and none of them had a visit for HIV management in the past year, their HIV viral load were classified as detectable. Results from the total sample showed that 45 (67%) of the mothers had detectable viral loads and 22 (33%) had undetectable viral loads).

**Family Management of the Child’s Illness**

Three variables were used to measure family management of the child’s illness: Condition Management Ability; Condition Management Effort; and Family Life Difficulty.

**Condition management ability.** Condition Management Ability is the parent’s perception of the overall manageability to competently carry out the management of their child’s condition including knowing what needs to be done to take care of the condition and their ability competently to carry out the management of their child’s condition. Higher values mean the condition is viewed as more readily manageable. Scores ranged from 31 to 59. Mean of 46.75 and standard deviation 6.91. Cronbach’s alpha was .65. Mothers agreed that in the future they would be caring for their child’s condition (n=36;
53.7%); they knew how to perform this care (n=33; 49.3%); how to handle unexpected things (n=43; 62.4%); felt they were doing a good job taking care of their child’s condition (n=47; 70.1%) and developed a routine for their child (n=42; 62.6%). Mothers had mixed feelings about when to be more protective of their child. About half thought they knew when to be more protective. For many, having enough money to care for their child’s condition was a concern (n=30; 44.8%). Overall scores indicate that this study sample perceived that they had the ability and could competently carry out the management of their child’s condition.

**Condition management effort.** Condition management effort is the time and work needed to manage the child’s condition. Higher values mean more effort is expended in managing the illness. Scores ranged from 4-20. Cronbach’s alpha was .38. Mean of 11.10 and standard deviation of 3.72. As expected, mothers agreed that their child’s condition required frequent visits to the clinic (n=45; 67.2%) and a over a third thought it took a great deal of time to manage (n=24; 35.8%). Just over a third felt that it did not take a lot of organization to manage the child’s condition (n=24; 35.8%). Overall scores indicated that the perceived effort needed to manage the child’s condition did not take an overwhelming amount of time and work.

**Family life difficulty.** Family life difficulty addresses parents’ perceptions of the extent to which having a child with a chronic condition makes family life difficult. Higher values indicate more difficulty managing the condition. Scores ranged from 14-58. Mean 27.94 and standard deviation 10.56. Cronbach’s alpha was .83. Mothers did not perceive that it was hard to take care of their child’s condition (n=48; 71.6%); did not perceive that the child’s condition made family life difficult (n=39; 58.2%) and did not perceive that it was hard to get others to help in the care of their child (n=30; 44.8%). Mothers believed they could fit their child’s care into the usual family routine (n=48; 71.6%). Overall,
mothers did not perceive that family life was difficult because of their child’s condition.

**Child Outcome Measures (Child Clinical Data CD4 count and HIV viral load)**

The child HIV clinical outcome measure, CD4, was dichotomously coded in this child sample as mild or moderate to severe immune suppression. The CDC defines immune suppression in as mild, moderate or severe based on age (Appendix B). Within the total sample, 79% of the children showed mild immune suppression as indicated by CD4 counts, while the remainder showed either moderate (n=12; 17.9%) or severe (n=2; .03%) CD4 counts.

The HIV viral load in this child sample was dichotomized into detectable and undetectable. More than two-thirds of the sample had detectable viral loads (detectable n=45; 67%). Because the children in this sample were found to have at least mild immune suppression and nearly half (n=31; 46.2%) had detectable viral loads, it is clear that the children studied had HIV disease that was not well-controlled.

**Covariates**

Univariate analyses were conducted to determine if three identified potential covariates were confounders of the conceptual model. The proposed covariates were: 1) whether the parent has assistance in managing her child/children within the home (i.e. a live in spouse, partner, family member or friend), 2) HIV disclosure status, and 3) whether the mother takes medication for her own HIV. Correlation coefficients were used to determine the strength of the relationships among the variables studied. Since none of the correlation coefficients for assistance in managing child/children at home, HIV disclosure status and mother’s taking HIV medication were found to be statistically significant, when examined in comparison to the outcome variables, they were not included in the subsequent multivariate regression analyses.”
Analysis by Specific Aims and Hypotheses

The following section presents the results from the 4 primary specific aims and hypotheses. A secondary aim describing maternal perception of stigma will be reported in this section. Appendix C presents a summary of the quantitative measures used for this study and provides information on score interpretation, minimum, maximum, mean, standard deviation, comparative literature, internal consistency (Cronbach’s alpha-α), skewness and standard error.

Specific Aim 1. To evaluate the relationship between maternal factors and family management.

Hypothesis 1a: Mothers who report poorer quality of life, higher levels of depression and poorer self care will report decreased ability in managing their child’s illness.

Hypothesis 1b: Mothers who report poorer quality of life, higher levels of depression and poorer self care will report increased difficulty in managing their child’s illness.

Hypothesis 1c: Mothers who report poorer quality of life, higher levels of depression and poorer self care will report increased effort in managing their child’s illness.

The first specific aim of the study sought to evaluate the relationship between maternal factors and family management of the child’s illness. A series of direct-entry, multiple regression analyses (MRAs) were used to address the specific aim (Stevens, 2002; Tabachnick & Fidell, 2012). Three criteria were employed: condition management ability, family life difficulty, and condition management effort. Therefore, three direct-entry MRAs were completed, one for each criterion (dependent variable). Predictors for all three analyses consisted of the following 11 maternal factors: maternal HIV viral load; Quality of Life health domain sub-scales (physical functioning; role-physical; bodily pain; general health; vitality; social functioning; role-emotional, mental health); self-care; and depression.
First MRA for Specific Aim 1. The first MRA examined relationships between maternal factors and the family-management criterion of condition management ability. Distributional statistics (means, standard deviations) are presented in Table 4.2 for the predictors and criterion. Results from the MRA are summarized in Table 4.3. The overall association was statistically significant, \( F(11, 55) = 8.09, p = .001 \). The overall relationship (\( R^2 = .618 \)) showed a large effect size using Cohen’s (1988) standards where \( R^2 \geq .509 \) represents a large effect size, \( R^2 = .361 \) denotes a medium effect size, and \( R^2 \leq .140 \) signifies a small effect size. The \( R^2 \) indicates that the predictors, as a set, account for 61.8 percent of the variation in the criterion’s variance.

Four predictors made statistically-significant, unique contributions to the estimation of the condition management ability criterion: bodily pain, general health, vitality and self care (all four \( p \leq .05 \)). The contribution of the independent variables was evaluated through the interpretation of standardized beta coefficients (Keith, 2006), where \( \beta \geq .25 \) represents a large effect size, \( \beta = .10 \) denotes a medium effect size, and \( \beta \leq .05 \) signifies a small effect size. All four statistically-significant predictors showed large effect sizes.
Table 4.3

Direct-Entry Regression Analysis for Maternal Variables Predicting Condition Management Ability

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<td>General Health</td>
<td>.188*</td>
<td>.076</td>
<td>.309</td>
</tr>
<tr>
<td>Vitality</td>
<td>-.198*</td>
<td>.075</td>
<td>-.319</td>
</tr>
<tr>
<td>Social functioning</td>
<td>-.011</td>
<td>.083</td>
<td>-.018</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>-.018</td>
<td>.109</td>
<td>-.036</td>
</tr>
<tr>
<td>Mental health</td>
<td>.080</td>
<td>.086</td>
<td>.154</td>
</tr>
<tr>
<td>Self-care</td>
<td>2.169***</td>
<td>.493</td>
<td>.604</td>
</tr>
<tr>
<td>Depression</td>
<td>.074</td>
<td>.083</td>
<td>.142</td>
</tr>
</tbody>
</table>

*Note: $B =$ unstandardized beta coefficient, SE $B =$ standard error of the unstandardized beta coefficient, $\beta =$ standardized beta coefficient. Numbers rounded at third decimal point for convenient presentation.

* $p = .05$, ** $p = .01$, *** $p = .001$. 
It was hypothesized that mothers who report poorer quality of life, higher levels of depression and poorer self-care will report decreased ability in managing their child’s illness. There were a total of four maternal factors (three quality of life factors—bodily pain, general health and vitality; and self-care), which contributed significantly to the model. Bodily pain was a negative coefficient which indicated that the less pain a woman experiences, the less difficulty she perceives regarding management of her HIV infected child. Pain is a known factor in ability to complete daily activities including those including care of the child (Dodd, et al. 2001). Likewise, vitality was also a negative coefficient, which indicated that the less vitality the woman had the more able she was to manage her child’s condition. Intuitively this does not make sense. We would have expected that a woman with vitality (i.e. energy) would have better ability to manage her child’s condition. There are two possibilities for this finding: 1) the result is real but not readily understandable and 2) we are seeing significance where there is none (Type 1 error). General health and self-care were positive coefficients which indicates the better a woman perceived her general health and self-care capacity the better her ability to manage her child’s condition. Thus the hypothesis was partially met. Additional discussion will follow in Chapter 5.

**Second MRA for Aim 1.** The second MRA examined relationships between maternal factors and the family-management criterion of family life difficulty. Results from the MRA are summarized in Table 4.4. The overall association was statistically significant, $F (11, 55) = 5.75, p = .001$. The overall relationship ($R^2 = .535$) showed a large effect size using Cohen’s (1988) standards where $R^2 \geq .509$ represents a large effect size, $R^2 = .361$ denotes a medium effect size, and $R^2 \leq .140$ signifies a small effect size. The $R^2$ indicates that the predictors, as a set, account for 53.5 percent of the variation in the criterion’s variance.
Three predictors made statistically-significant, unique contributions to the estimation of the family life difficulty criterion: bodily pain ($p=\leq .05$), role-emotional ($p=\leq .05$), and self-care ($p=\leq .05$). The contribution of the independent variables was evaluated through the interpretation of standardized beta coefficients (Keith, 2006), where $\beta > .25$ represents a large effect size, $\beta = .10$ denotes a medium effect size, and $\beta \leq .05$ signifies a small effect size. All three statistically-significant predictors showed large effect sizes.

We hypothesized that mothers who report poorer quality of life, higher levels of depression and poorer self-care will report increased difficulty in managing their child's illness. There were a total of three maternal factors (two quality of life factors—bodily pain, role-emotional and self-care) which contributed significantly to the model. Bodily pain was a positive coefficient, which indicated that the more pain a woman experiences, the more she would experience family life difficulty in the context of having a child with chronic illness. Role-emotional and self-care were positive coefficients. The role-emotional variable indicates health related role-limitations in terms of time spent doing work or other usual activities, the amount of work accomplished and the care with which work and other activities were performed. In this sample the coefficient was in the negative direction indicating the more emotional health related role limitations would increase the amount of family life difficulty. Likewise, mothers who perceived decreased capacity for self-care would expectedly experience an increase in family life difficulty. Thus, the hypothesis was partially met. Additional discussion will follow in Chapter 5.
Table 4.4

Direct-Entry Regression Analysis for Maternal Variables Predicting Family Management Difficulty

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>SE $B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>52.071</td>
<td>10.792</td>
<td></td>
</tr>
<tr>
<td>Maternal HIV Viral Load</td>
<td>-2.425</td>
<td>2.212</td>
<td>-.109</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>-.145</td>
<td>.125</td>
<td>-.157</td>
</tr>
<tr>
<td>Role-physical</td>
<td>.329</td>
<td>.230</td>
<td>.355</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>.312**</td>
<td>.110</td>
<td>.347</td>
</tr>
<tr>
<td>General health</td>
<td>-.154</td>
<td>.129</td>
<td>-.166</td>
</tr>
<tr>
<td>Vitality</td>
<td>.075</td>
<td>.126</td>
<td>.079</td>
</tr>
<tr>
<td>Social functioning</td>
<td>-.002</td>
<td>.140</td>
<td>-.002</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>-.504**</td>
<td>.184</td>
<td>-.657</td>
</tr>
<tr>
<td>Mental health</td>
<td>-.090</td>
<td>.146</td>
<td>-.113</td>
</tr>
<tr>
<td>Self-care</td>
<td>-1.764*</td>
<td>.831</td>
<td>-.322</td>
</tr>
<tr>
<td>Depression</td>
<td>.025</td>
<td>.140</td>
<td>.032</td>
</tr>
</tbody>
</table>

**Note:** $B$ = unstandardized beta coefficient, SE $B$ = standard error of the unstandardized beta coefficient, $\beta$ standardized beta coefficient. Numbers rounded at third decimal point for convenient presentation.
Third MRA for Aim 1. The third MRA examined relationships between maternal factors and the family-management criterion of condition management effort. Results from the MRA are summarized in Table 4.5. The overall association was statistically significant, $F(11, 55) = 2.58, p = .001$. The overall relationship ($R^2 = .410$) showed a medium effect size using Cohen’s (1988) standards where $R^2 > .509$ represents a large effect size, $R^2 = .361$ denotes a medium effect size, and $R^2 \leq .140$ signifies a small effect size. The $R^2$ indicates that the predictors, as a set, account for 41.0 percent of the variation in the criterion’s variance.

Two predictors made statistically-significant, unique contributions to the estimation of the condition management effort criterion: General health and Mental health (both $p$s < .05). The contribution of the independent variables was evaluated through the interpretation of standardized beta coefficients (Keith, 2006), where $\beta > .25$ represents a large effect size, $\beta = .10$ denotes a medium effect size, and $\beta \leq .05$ signifies a small effect size. Both statistically-significant predictors showed large effect sizes.

We hypothesized that mothers who report poorer quality of life, higher levels of depression and poorer self care will report increased effort in managing their child’s condition. There were a total of two maternal factors (two quality of life factors-general health and mental health), which contributed significantly to the model. Both general health and mental health were negative coefficients indicating that for mothers who have decreased general health and decreased mental health they would experience increased effort in managing their child’s condition. Thus, the hypothesis was partially met. Additional discussion will follow in Chapter 5.
Table 4.5

Direct-Entry Regression Analysis for Maternal Variables Predicting Condition Management Effort

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>24.245</td>
<td>4.283</td>
<td></td>
</tr>
<tr>
<td>Maternal HIV viral load</td>
<td>-.706</td>
<td>.878</td>
<td>-.090</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>.027</td>
<td>.049</td>
<td>.083</td>
</tr>
<tr>
<td>Role -physical</td>
<td>-.014</td>
<td>.091</td>
<td>-.041</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>.047</td>
<td>.044</td>
<td>.147</td>
</tr>
<tr>
<td>General health</td>
<td>-.115*</td>
<td>.051</td>
<td>-.349</td>
</tr>
<tr>
<td>Vitality</td>
<td>.005</td>
<td>.050</td>
<td>.016</td>
</tr>
<tr>
<td>Social functioning</td>
<td>.036</td>
<td>.055</td>
<td>.111</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>-.100</td>
<td>.073</td>
<td>-.371</td>
</tr>
<tr>
<td>Mental health</td>
<td>-.148*</td>
<td>.058</td>
<td>-.529</td>
</tr>
<tr>
<td>Self-care</td>
<td>.125</td>
<td>.330</td>
<td>.065</td>
</tr>
<tr>
<td>Depression</td>
<td>-.082</td>
<td>.055</td>
<td>-.291</td>
</tr>
</tbody>
</table>

*Note: B = unstandardized beta coefficient, SE B = standard error of the unstandardized beta coefficient, β standardized beta coefficient. Numbers rounded at second decimal point for convenient presentation.

* p = .05, ** p = .01, *** p = .001.
Specific Aim 2. To evaluate the relationship between the maternal factors and child outcomes.

Hypothesis 2. Children whose mothers who report poorer quality of life, higher levels of depression, and poorer self-care will have decreased CD4 counts and high viral load measures.

The second specific aim of the study sought to evaluate whether maternal factors influence child clinical outcomes. Two binary logistic regression analyses were used to address this specific aim. One criterion was children’s CD4 count and the other was children’s HIV viral load. Predictors for both analyses were the same and comprised the following 11 maternal factors: maternal HIV viral load; quality of life sub-scales (physical functioning; role-physical; body physical; general health; vitality; social functioning; role-emotional; mental health); self-care, and depression.

The first binary logistic regression analysis was used to assess the association between maternal factors and the child clinical outcome of CD4 count. The overall association was statistically significant, $\chi^2 = 20.270$, $df (11)$, $p = .042$. The overall relationship (Cox & Snell $R^2 = .261$) showed a medium-to-large large effect size using Cohen’s (1988) standards where $R^2 > .509$ represents a large effect size, $R^2 = .361$ denotes a medium effect size, and $R^2 < .140$ signifies a small effect size.

Only one maternal predictor made a statistically-significant, unique contribution to the estimation of the criterion: depression ($p = .031$). The contribution of this independent variable was evaluated through the interpretation of its odd ratio in relationship to the base rate of subjects who received a value of 1 on child CD4 count (Allen & Le, 2008). Results showed a small effect size. Analysis revealed an odds ratio of 1.136 with a 95%
confidence interval of 1.012-1.275 based on the presence or absence of immune function. It was hypothesized that children whose mothers report poorer quality of life, higher levels of depression, and poorer self-care would have decreased CD4 counts and high viral load measures. This analysis indicated that women who had more depression were more likely to have children who were more immune suppressed. This makes sense as depression may negatively impact how mothers care for their children in the context of their HIV disease. The hypothesis was partially met.

The second binary logistic regression analysis was used to assess the association between maternal factors and the child outcome of HIV viral load. The overall association was statistically significant, $\chi^2 = 34.302, df (11), p = .001$. The overall relationship (Cox & Snell $R^2 = .401$) showed a medium-to-large large effect size using Cohen’s (1988) standards where $R^2 \geq .509$ represents a large effect size, $R^2 = .361$ denotes a medium effect size, and $R^2 \leq .140$ signifies a small effect size.

Four predictors made a statistically-significant, unique contributions to the estimation of the child HIV viral load outcome: Maternal HIV viral load ($p = .001$), self-care ($p = .01$), depression ($p = .001$), and QOL (physical functioning)($p = .04$). The contribution of these independent variables were evaluated through the interpretation of its odd ratio (OR) in relationship to the base rate of subjects who received a value of 1 on HIV viral load (Allen & Le, 2008). Results showed a large effect size for three predictors: maternal HIV viral load, self-care, and depression. The last significant predictor physical functioning showed a small effect size.

We hypothesized children whose mothers report poorer quality of life, higher levels of depression, and poorer self care would have lower CD4 counts and higher viral loads. Analysis for maternal HIV viral load revealed an odds ratio of 56.94 with a 95%
confidence interval of 5.141-630.723 indicating that mothers with increased HIV viral loads were more likely to have children with increased HIV viral loads. Analysis for capacity for self-care revealed an odds ratio of .340 with a 95% confidence interval of .149-.774 indicating the mothers who reported lower capacity for self-care were more likely to have children with increased HIV viral loads. Analysis for depression revealed an odds ratio of .802 with a 95% confidence interval of .692-.928 indicating that mothers who reported lower depression scores had children with detectable viral loads. This too was an unexpected finding. A type 1 error is possible or if the finding is truly significant, it will require further exploration. This will be discussed in chapter 5. Analysis for physical functioning (QOL) revealed an odds ratio of .867 with a 95% confidence interval of .756-.995 indicating that mothers reporting less physical limitations were more likely to have children with decreased HIV viral loads. For this aim, the hypothesis was partially met. All findings will be discussed further in chapter 5.
Specific Aim 3

Specific Aim 3. To evaluate the relationship between family management and child outcomes.

Hypothesis 3a: Children whose mothers report increased effort in family management have decreased CD4 counts and high viral load measures.

Hypothesis 3b: Children whose mothers report increased difficulty in family management have decreased CD4 counts and high viral load measures.

Hypothesis 3c: Children whose mothers report less ability in family management have decreased CD4 counts and high viral load measures.

The third specific aim of the study sought to evaluate whether family management of the child’s illness was related to child clinical outcomes. There were two outcome variables: children’s CD4 count and children’s HIV viral load. Binary logistic regression analysis was used to assess the relationship between family management variables: condition management ability, family life difficulty and condition management effort and the outcome variable, children’s CD4 count. The overall association was not statistically significant, \( \chi^2 = 2.120, df (3), p = .548 \).

A second binary logistic regression analysis was used to assess the relationship between family management variables: condition management ability, family life difficulty and condition management effort and the outcome variable, children’s HIV viral load. The overall association was not statistically significant, \( \chi^2 = 0.430, df (3), p = .934 \).
In sum, results showed that the three potential mediators did not significantly predict performance on the two criteria of children’s CD4 count and children’s HIV viral load. The two findings do not bode well for the upcoming mediation analyses. Specifically, the predictors in the analyses for Aim 3 (condition management ability, condition management effort and family life difficulty) will be the mediators for Aim 4 mediation analysis. The criteria for Aim 3 and Aim 4 are identical.

A fundamental requirement of mediation analyses is that there is a statistically significant relationship between the mediators and criteria (Baron & Kenny, 1986; Bauer, Preacher, & Gil, 2006). Otherwise, the mediation analyses will fail. As demonstrated by the analyses just discussed, there is no significant relationship between any of the three mediators and the two criteria that will be used to address Aim 4. Thus, our hypotheses that children whose mothers report increased condition management effort, increased family life difficulty and decreased condition management ability would have poorer outcomes was not met.

Specific Aim 4. To evaluate whether the relationship between maternal factors and the child outcomes are attenuated by the presence of family management.

Hypothesis 4. Family management will mediate the relationship between maternal factors and child outcomes.

The primary hypothesis for Aim 4 was that family management will mediate the relationship between maternal factors and child clinical outcomes. In all, 12 mediation analyses were completed. These included maternal factors, which are independent variables (predictors), family management of the child’s illness variables (mediators) and child clinical outcomes (dependent variables/criterion).

All mediator models were assessed using the SPSS indirect script for bootstrapped, multiple mediator analyses developed by Preacher and Hayes (2008).
The procedure involves two parts: (1) investigating the total indirect effect, or deciding whether the set of mediators transmits the effect of independent variable (X) to dependent variable (Y); and (2) testing hypothesis regarding individual mediators in the context of a multiple mediator model. In a multiple mediation model, the likelihood of parameter bias due to omitted variables is reduced and including several mediators in one models help to determine the relative magnitudes of the specific indirect effects associated with all mediators (MacKinnon, Lockwood, & Williams, 2004).

Bootstrapping was employed because it is known to be most the powerful and reasonable method of obtaining confidence limits for specific indirect effects during mediation analyses (Briggs, 2006; Williams & MacKinnon, 2008). Bootstrapping involved repeatedly sampling from the data set and estimating the indirect effect in each resampled data set, thus bootstrapped analyses generally are appropriate for small samples, like the ones used in the current study (Yook, Kim, Suh, & Lee, 2010). Another advantage of bootstrapping is that it produces a nonparametric test of the mediation effect (the cross product of the predictor x the mediator). From the original dataset, 5,000 identically sized datasets were created by randomly drawing participants and replacing each value as it was sampled. Confidence intervals for the 5,000 mediator effects were then derived using z-score based bias corrections. In this approach, mediation is significant if the upper and lower bounds of these bias-corrected and accelerated (Efron & Tibshirani, 1993) confidence intervals do not contain zero.

Unfortunately, results across the 12 mediation analyses were uniform and showed that none of the analyses produced a statistically significant mediation effect. The obtained findings for Aim 4 were disappointing, but anticipated in the sense that results from Aim 3 showed that the three mediators include: condition management ability, condition management effort and family life difficulty, failed to have significant
relationships with the two primary criteria of children’s CD4 count and children’s HIV viral load. Thus, our hypothesis that family management factors (condition management ability; family life difficulty and condition management effort) would mediate maternal factors and child outcomes was not met.
Secondary Aim. To describe maternal perception of stigma regarding: concerns about consequences of others knowing their HIV status; concerns about disclosure; self image; and public perception of HIV.

This secondary aim sought to describe maternal perception of stigma regarding: concerns about consequences of others knowing their HIV status; concerns about disclosure; self image and public perception of HIV. While the concept of stigma is not included in the Model, as noted earlier, stigma is pervasive in society and is markedly present in HIV disease. A description of how mothers perceive stigma is a concept to be explored and incorporated into potential interventions for HIV affected families. For the total HIV Stigma Scale, four subscales were administered and scored. For the personalized stigma subscale scores can range from 18-72. For the disclosure subscale scores can range from 10 to 40. For the negative self-image subscale, scores can range from 13-52 and for the public attitudes subscale, scores can range from 20 to 80.

Only 65 of the 67 mothers completed the entire questionnaire. Two mothers were unable to complete the total questionnaire. Both mothers cited that the questions evoked negative emotions and were able to complete only part of the measure.

Personalized stigma. The Personalized Stigma Subscale scores ranges from 19 to 70. Mean was 42.69 and standard deviation was 12.33. Cronbach’s alpha was .94. Most mothers reported they perceived that people with HIV are rejected when others find out (n=56; 83.5%) but most did not feel that people they personally knew grew distant (n=36; 53.7%). Many mothers felt hurt by the reactions of others to her HIV status (n=38; 56.7%) and had regret for telling others about her HIV (n=40; 59.7%). Most mothers did not believe that people they cared about were not outwardly discriminatory towards them.
(n=47; 70.1%). They noted they had not lost friends since sharing their HIV status and had not stopped socializing (both n=36; 53.7%). In summary, stigma was very personalized for mothers in this study. Mothers perceived that they were rejected when others found out about their HIV status and felt hurt by the reactions of others. Many mothers still felt persons closest to them were supportive.

*Disclosure.* Disclosure subscale scores ranged from 15-40 with a mean of 31.65 and standard deviation of 5.02. Cronbach’s alpha was .76. Most of the mothers reported that in many areas of her life, no one knows they have HIV (n=54; 80.6%). They believed that telling people about their HIV was risky (n=49; 73%). Mothers worried about people discriminating against them (n=51; 76.1%) and worried that others would tell her HIV status (n=36; 53.7%). It appears that mothers were less worried about discrimination from persons closest to them as discussed in personalized stigma but those outside of the family brought worry about discrimination. While mothers had regret for telling their HIV status, most ultimately did not feel that telling others had been a mistake (n=34; 50.7%). Keeping HIV a secret was a priority (n=53; 79.1%). In fact, hiding this diagnosis was very important (n=54; 80.5%). Mothers wanted others who knew her HIV diagnosis to keep her status a secret as well (n=51; 76.1%). Overall, sharing HIV diagnosis was a worry for mothers and keeping the diagnosis a secret was a priority.

*Negative self-image.* Negative self-image subscale scores ranged from 13-46 with a mean of 31.82 and standard deviation of 7.85. Cronbach’s alpha was .85. Mothers in this study felt guilty for having HIV (n=40; 59.7%). Most did not feel that they were less of a good person because of HIV (n=48; 71.6%) and did not feel ashamed because of HIV (n=43; 64.2%). Most believed that a person who has HIV is dirty (n=56; 83.5%) and that people perceived them as disgusting (n=46; 68.6%). Most worried about being discriminated against (n=51; 77.6%) and feel that they had to hide the fact that they had
HIV (n=53; 79%). Feeling isolated from the world was nearly equal (isolated n=36; 54.5%; not isolated n=31; 46.9%) It appeared that while mothers felt very affected at a personal level, but internally they did not feel as if they were a bad person. This may have been a function of insulating oneself against these negative feelings for daily coping.

**Public attitudes.** Public attitudes subscale scores ranged from 22-80 with a mean of 53.02 and standard deviation of 11.39. Cronbach’s alpha was .92. Mothers believe that people with HIV lose their jobs when their employers find out (n=39; 58.2%). They also believe that most people are uncomfortable around someone with HIV (n=52; 78.7%). In summary, mothers believed that public attitudes are largely negative. Many of the mothers in this sample did not work. While there are many factors which contribute to not working, fear of job loss and fear of how others might perceive them if HIV status is known are to be considered.
CHAPTER 5

Discussion

Some studies suggest that maternal factors affect the way in which a mother cares for her own chronic illness and may affect how she cares for her child's illness (Buchacz, Rangel, Blacher & Brooks, 2009; Cohen, 1995; Hackl, Somlai, Kelly & Kalichman, 1997; Ledlie, 1999; Lesarman, 2008; Lewis, 2001; Mellins & Erhardt, 1994).

To our knowledge, this is the first study known to examine how maternal factors affect family management of the child's illness and child clinical outcomes when both the mother and child have HIV. It is also the first study to examine how family management of the child's illness may mediate child outcomes between maternal factor and child outcomes. As such, it adds important information to the body of literature on HIV infected mothers and their HIV infected children.

We aimed to describe the maternal factors and family management factors that influence child outcomes and whether the family management of the child's illness factors of condition management ability; family life difficulty and condition management effort mediated the process in this sample. As a secondary aim, we explored the concept of stigma and described how it affected mothers in this sample. Additionally, we explored stigma as a process external to the intra-family processes in the Vincent Model.

In this chapter, we present 1) the major and secondary findings of the study based on the study aims and variables within those aims, 2) a discussion which compare the findings to the literature, 3) a discussion of the Vincent Model, 4) major strengths and limitations and, 5) suggestions for future research.

Summary of Major and Secondary Findings
The participants in this study were biologically related, HIV infected mothers and their HIV infected children (n=67). Mothers identified as female (100%); African-American/Black (79.1%) and were of non Hispanic/Latina ethnicity (95.5%) with a mean age of 37.06 years. The majority of women completed 12th grade or had higher education (74.6%), were never married (47.8%), were not living with a partner or spouse (88.1%) and had an average of 3.37 persons living in their home (range 1-7 persons not including the mother). Just over half worked outside the home (50.7%) and reported income of less than $15,000 dollars/year (67.2%). The mean number of years the mothers were living with HIV was 11.09 years. Most mothers declared a religious affiliation (77.6%). Thirteen (19.4%) women had not had a health care visit for HIV management in over one year. Overall, participants had demographic characteristics similar to the demographic of the U.S. population affected by HIV and of other studies examining HIV infected women (CDC, 2010b; 2010c).

**Findings by the aims and variables**

The primary and secondary findings of the study are presented by discussing each aim and associated variables. The primary aim 1 analysis, which examined maternal factors on family management criterion of ability, difficulty and effort variables showed overall significance as did the analysis of primary aim 2 which examined maternal factors and child outcomes. Both primary aim 1 and primary aim 2 also had individual factors, which contributed significantly to the model. The aim 3 analysis did not reveal a relationship between family management factors and child outcome, which then did not meet the hypothesis. Subsequently, as a result of aim 3 analysis results, it was expected that the final primary aim (aim 4) would be unable to be answered since mediation did not exist. A discussion of the specific findings and how these findings contribute to the literature is organized by specific aim.
Primary Aim 1: Maternal Factors and Family Management

Primary aim 1 explored the relationship of maternal factors and family management of the child’s illness factors of condition management ability; family life difficulty and condition management effort. The first analysis of primary aims 1 explored maternal factors and condition management ability. Factors, which made statistically significant, unique contributions, were three quality of life factors: bodily pain, general health and vitality; and self-care. All four factors showed large effect sizes. In this sample, the majority of women reported that they had bodily pain (79.1%) ranging from mild to very severe. Women also reported that pain interfered with their normal work inside and outside the home (67.1%). This analysis showed that less bodily pain indicated the woman had the ability to manage her child’s condition.

The second factor making a unique contribution to a mother’s ability to manage her child’s condition was general health. General health in this study was reported by most women as good, very good or excellent (75%). The analysis showed that when women perceived better general health the better their ability to manage their child’s condition.

The third factor making a unique contribution to a mother’s ability to manage her child’s condition was self-care. Self-care showed the most significance of the four variables (p=.001). Women who perceived higher capacity for self-care were able to manage their child’s condition. In this sample, women perceived they had capacity for self-care with a score of 6 or higher (86%). There are no studies, which looked at capacity for self-care using the PSCS. In this population, it was clear that women identified that they perceived capacity for self-care. In the literature, there was a study which examined self-care in HIV infected women which linked self-care as a motivation in staying healthy and continuing to live (Shambley-Ebron & Boyce, 2006). The lack of studies examining self-care and self-management in this population highlights the need
to continue study in this population. This study noted that self-care and the women’s perceived capacity was significant in her ability and difficulty in managing her child’s illness.

The fourth factor making a unique contribution to a mother’s ability to care for her child was a quality of life factor, vitality. Vitality measured fatigue and energy level. In this sample women reported that they had high levels of fatigue at least some of the time (79%). This was expected based on the literature. However, the analysis revealed a non-intuitive unexpected finding. Vitality ($p \leq .05$) was significant. The analysis showed that women reporting less vitality had increased ability to manage their child’s condition. This could, as noted before, be a Type 1 error (i.e. seeing significance when there is none), or it could be a real finding. Based on other significant factors in this analysis, it could be further hypothesized that women reporting this had used up all of their energy on other tasks such as their own self-care or other behaviors. This would deplete her own energy yet not affect her energy to be able to care for her child. There is nothing evident in the literature to support this finding. Further exploration is needed.

The second analyses of primary aim 2 explored maternal factors and family life difficulty. There were three factors, which made significant, unique contributions to family life difficulty: two were quality of life factors—bodily pain and role-emotional and self-care (all three $p$’s were $\leq .05$). Bodily pain in this case indicated the more pain, the greater the increase in family life difficulty. Role-emotional indicated health related role limitations. The more role-emotional limitation, the more family life difficulty would be experienced. Research supports that women are at higher risk for poor mental health including role limitations associated with mental health and extensive physical symptoms such as pain (Dodd, et. al. 2001; Holzemer, 2002; Holzemer, Hudson, Kirksey, Hamilton & Bakken, 2001). In the self-care analysis it was noted that if a women perceived decreased
capacity for self-care, she would experience increased family life difficulty.

The third analyses of primary aim 1 explored maternal factors and condition management effort. Two quality of life factors—general health and mental health were significant ($p \leq .05$). Women who perceived decreased general health and decreased mental health (i.e. general psychological well-being) would experience increased effort in managing their child’s condition.

The findings associated with primary aim 1 provides support for a study by Santacroce and colleagues (2002), which notes that how mothers manage psychosocial issues is interwoven in management of their child’s illness. The literature supports that social functioning is problematic in the population of women with HIV (Plach, Stevens & Heidrich, 2006). This study did not support that finding. The quality of life domain of social functioning was not significant in this sample. This was not surprising as most women in this study noted that despite their HIV they continued to socialize and that this did not affect their physical health or emotional health. Perhaps as more persons are educated about HIV, the more comfortable women will become in their daily lives. Another factor may have been that women in this sample, on average, had HIV for 11 years; thus, giving them time to adjust to their diagnosis.

**Primary Aim 2 Maternal Factors and Child Outcomes**

Primary aim 2 explored the relationship of maternal factors and child outcomes. In the study, depression was the only significant factor associated with the child outcome of child CD4 count. There were three significant factors which affected the child outcome of child HIV viral load. These were maternal viral load ($p=.001$), self-care ($p=.01$), depression ($p=.001$) and QOL-physical functioning ($p=.04$). As maternal viral load increased, the child’s viral load increased. This too was an unexpected finding. One study in HIV infected women noted that they may give caregiving priority to their child.
instead of attending to their own health care needs (Tufts, Wessell & Kearney, 2010). The findings of this study were to the contrary. While it was hypothesized that most mothers would take care of their child first indicating viral suppression, both the mother and the child in this study showed increased maternal viral load and an increased child viral load indicating the contrary. A possible explanation for this could include that both are not taking medications as prescribed and as such, both have high viral loads. Another explanation for this includes viral resistance to medications. Women who reported lower capacity for self-care and decreased physical functioning had children with higher viral loads. These findings were expected and supported by the maternal literature. Care-giving responsibilities for dependent children have been associated with decreased adherence to self-care regimens including taking medications (Holstad, Dilorio & Magowe, 2006; Tufts, Wessell & Kearney, 2010). Women who perceived lower capacity for self-care may take care of their child but not the HIV management part of caring for their child including giving medications which results in high viral load indicating poor viral suppression. These findings are significant. The contributing reasons for these findings require further study as poor viral suppression will eventually lead to poor outcomes.

Women, who reported lower depression scores indicating less depression, had children with higher viral loads. This was also a non-intuitive, unexpected finding, which will require further exploration. Depression was a common finding in this study. Most women (52.2%) reported depression scores >16 which indicated risk for depression on the CES-D scale. Of the women who reported depression, 6% had scores 16-21; 46% had scores greater than 22. It is possible that due to small sample size the women who fell in the mid-range may have been influential cases and affected the model despite SPSS diagnostics to the contrary. Again, further exploration is required to discuss this
Primary Aim 3: Family Management and Child Outcomes

The third specific aim sought to evaluate whether family management of the child’s illness was related to child clinical outcomes. The results of this analysis were insignificant thereby negating any association between family management factors and child clinical outcomes. The results were insignificant thereby negating the hypothesis that family management factors affected child clinical outcomes. It is possible that the reason this did not show significance was due to the type of child outcomes studied which were clinical, physiologic outcomes as opposed to psychosocial outcomes. The FaMM, in validation, used child and family psychosocial functioning correlates and not physiologic correlates or outcomes (Knafl, Deatrick, Gallo, Dixon, Grey, Knafl & O’Malley, 2011). Further study in a larger sample may reveal significance and requires additional exploration.

Primary Aim 4: Family Management of a Mediator between MF and CO

As expected from the results of the aim 3 analysis, there were no significant findings from the analysis of family management and child outcomes. As a result, the final primary aim (aim 4) was unable to be answered since mediation did not exist. While we know from the vast body of literature on the Family Management Model, it is possible that the type of child outcomes studied (clinical physiologic outcomes) were the issue. Most of the studies showing significance of this model looked more at psychosocial outcomes. The small sample size may also be at play here and prevents us from detecting any findings.

The three proposed covariates: 1) whether the mother has assistance in managing her child/children within the home (i.e. a live-in spouse, partner, family member or friend), 2) the nature of the mother’s HIV disclosure status; and 3) whether the mother
takes medication for her own HIV. These potential covariates did not contribute to multiple univariate analyses and did not contribute to the overall model. While these findings are surprising, they were not unexpected due to the small sample size. One confounder approached significance; whether the mother takes medication for her own HIV. Each of these factors has been discussed as important in the literature (Hudson, et al, 2001; Serovich, Kimberly, Mosack, & Lewis, 2012) and clinically make sense that they would affect child outcomes; but this study did not support these findings. While it was not statistically significant, as noted, many women reported greater depressive symptomatology when they had disclosed to their child (Brackis-Cott, et al, 2007). In this sample, 51.4% of the women reporting depressive scores >16 (n=35) also had disclosed to their children. Further study is needed.

**Secondary Aim Findings**

Overall, it is clear that stigma is a very powerful force in the lives of women in this study. All four subscales had largely worrisome findings. Guilt, shame, isolation, fear, and rejection continue to be incorporated in how women think about their HIV disease. At a personal level, women felt supported by people close to them but in general felt a sense of rejection. Disclosure of HIV status was perceived as significantly risky and posed the worry of discrimination both in their families and in interactions external to family. Women had an overall negative self-image. They believed that people thought they were dirty, perceived HIV as disgusting and felt the need to hide their HIV. Women’s perception of public attitude towards HIV was fear of loss of job and discrimination. Many women noted regret for sharing their HIV diagnosis but most ultimately did not feel it was a mistake to tell. This finding supports the concept that once the information has been disclosed, it lifts the burden of secrecy, which can contribute to
daily stressors for families living with HIV. In this sample, women reported depression and more than half reported difficulty with role-emotional issues such as accomplishing less than they would have liked and cut down on the things they normally do. A study by Thorne, Paterson & Russell (2003) noted that HIV associated stigma and related emotional issues affected day-to-day self-management in HIV disease and for persons with HIV and their families. This study supports that HIV associated stigma is significant and that emotional issues such as depression which affected child’s CD4 outcome and the quality of life factor (role-emotional) affected family life difficulty. Capacity for self-care was also significant in family management factors of condition management ability and family life difficulty, which also supports these findings. Stigma, over 30 years later in this HIV epidemic, still has significance for those living with the disease as identified in this study.

**Vincent Conceptual Model**

The Model used for this study was developed based on the current chronic illness and HIV literature. The premise of the Model was that maternal factors affect family management and ultimately child outcomes in HIV infected women and their children. The Model proposed that family management factors mediated the effect of maternal factors on child outcome areas. While the data identified trends in areas of study needed to test hypotheses, only three of the primary aims yielded data, which only partially met the study hypotheses. The Model, consisting of three conceptual parts, suggested factors, which might have affected a child’s clinical outcomes. Namely, these factors were maternal factors and family management of the child’s illness factors. While the data from the analyses of this Model showed that there were overall significant associations between maternal factors and family management ,and maternal factors
and child outcomes, as well as unique contributors to these parts of the conceptual model, there were no significant overall or unique associations between family management and child outcomes. These factors included the quality of life factors of physical functioning, role-physical (physical factors affecting daily work), and social functioning did not emerge as important in this study. While these factors were believed to be important, as described earlier in Chapter 2, they did not show significance in this Model. Social functioning did not emerge as a significant factor and as noted, women did not report social functioning difficulty. Physical functioning, with the exception of the physical symptom of bodily pain, was also not significant in this study. Perhaps the reason for these findings is supported in studies noted by Plach, et al (2006). The authors suggest that physical functioning and psychosocial factors are inter-related. The quality of these experiences within their social role is an important factor in adaptation to chronic illness and that high social role quality can mediate and moderate the effect of physical health on psychological well-being (Plach, et al. 2006), which is possibly why depression and physical health were not strongly predictive of family management of the child’s illness and subsequent child outcomes. The lack of significance these factors in this Model does not discount their importance but points to the need for further study to validate these findings in an adequate sample size.

As discussed earlier, these factors were noted as important in previous studies. However, this does not lessen their importance but rather shows that this did not support their contribution to this Model. What the Model does illustrate is that certain maternal factors are associated with family management of the child’s illness and child outcomes. These factors were namely, maternal HIV viral load; depression, self-care and quality of life factors (bodily pain, physical functioning, general health, vitality, role-emotional and mental health). In light of the sample size, these findings help to identify trends to
continue to explore. The Vincent Model needs to be modified and refined to further explore HIV infected mothers and their HIV infected children. The Model may also have some usefulness in other categorical and non-categorical chronic illness populations where both the mother and child are affected. Considerations for this would be to specify the Model to incorporate disease specific measures or to make the Model more generic for use in all chronic illness populations. Sample size must also be sufficient to reveal associations.

**Strengths and Limitations of the Study**

There were many strengths and limitations to this study. The plan for analysis of data was based on a power analysis, which required a minimum of 100 participants. The sample size (n=67) was smaller than expected making it more challenging to draw statistical inferences. Despite the small sample size, it provided adequate power to evaluate the primary specific aims. The study was non-experimental. As such, the risk exists that association between the independent and dependent variables would not be detected even though it is possible the association existed. In some cases, however, the association may have been present but not true. The significance level was set at .05 to minimize this issue and although not predictive, it revealed findings and trends which can be further studied. This was a cross-sectional study so as anticipated, there was no lost to follow up and through quality assurance methods used to monitor data, there was minimal missing data.

The small sample size was a result of several factors. Despite best intentions, participating clinics may have overestimated the number of eligible subjects. The sample was a convenience sample. As described earlier, some women did not participate. As with any study, individuals self-select to participate in a study, which may add sample bias. Subjects were compensated for their time in this study at a level commensurate
with their effort as approved by the IRB. The reasons women did not participate is of concern as it may not truly reflect the reason for non-participation. While it is true that women are busy and have other responsibilities, mistrust of the medical community, fear of disclosure and felt stigma may contribute to not participating in studies. The mothers who did not participate are a population of interest because the reasons they don’t participate may provide unique insight on such issues as why they may not access health care. While this sample’s education level was primarily above an 8th grade education level, low education level and subsequent low literacy is still of concern.

Identifying research methods to engage women without barriers is challenging. Racial and ethnic disparities are also of concern.

An additional strength was that the study represented data from four clinics in areas where HIV is prevalent. The sample did reflect the national trend in individuals affected by HIV. The length of time to complete the questionnaires was both a strength and a weakness. It was estimated that it would take 50 minutes to complete the questionnaires when in reality it took most of the women less than 40 minutes to complete. The amount of time could have been viewed as burdensome by the women due to the nature of the questions. Anecdotally, women made many comments after completing the survey and the subsequent de-briefing to ensure there were no safety issues. Most of the comments were positive with themes that indicated women “want to be heard,” “want to tell you more,” “it’s about time someone cared what I think about living with this disease and taking care of my child,” and “finally, someone really wants to know how I feel. I am glad you asked me.” This speaks volumes about how women need to feel valued in their opinions and needs about their own and their child’s health. It also speaks to the need for additional qualitative study in the conceptual realm of what the experience is to live with a chronic illness while taking care of your child with chronic
illness. To take this a step further, exploring this experience when the disease is something that is transmitted from mother to child adds another dimension to this lived illness experience.

Study data were obtained with a combination of self-report and clinical measures. A majority of the factors, however, were measured with self-report questionnaires. Therefore, another limitation of the study was that the questionnaires were based on self report. This may affect reliability of the questionnaires as the participant may have had poor recall or report information to please the investigator. Although the questionnaires used in this study had a 5\textsuperscript{th} to 8\textsuperscript{th} grade literacy level, the majority of women in this study had a 12\textsuperscript{th} grade or higher education level. Many women, despite grade level, may not be able to read and comprehend the questionnaires, which could have affected the understanding of the content and resultant answers. One measure, the SF36v2 Health Survey, had a item called the RCI. This index indicated for this study, 92.5% of women scored their questionnaires to indicate good consistency of responses. While the measures used were validated in populations with HIV, there were no such indices for other measures used in this study.

With few exceptions, the questionnaires were available in Spanish and other languages. Because the population of HIV in the United States includes non-English speaking patients, many of whom are immigrants, including this group of individuals should be considered for future study.

**Additional Findings**
One of the most striking findings was the number of comments written in the margins of the questionnaires. Many comments validated what the question asked. However, the majority of the comments were directed at their feelings about their belief about God or a higher power in their life. All comments noted that this was a positive influence in their lives and helped them with their family life. One example was “If I didn’t have God, I don’t know how I would live through this.” This was not a surprising finding as many women declared an association with an organized religion. While there have been studies including religion and spiritual belief and its role in illness (Byrne & Honig, 2006; Coleman & Holzemer, 1999; Hudson, Lee & Portillo, 2001; Lesar & Maldonado, 1996; Pequegnat & Bray, 1997; Robinson, 1994) further study about how this influences families when both the mother and the child are affected by chronic illness is needed.

We did not directly collect information on mental health from the women (i.e. whether she has been diagnosed with a mental illness) or whether there was a history of or current substance use. Mental illness in HIV infected women is prevalent and can be a barrier to accessing health care (Aziz & Smith, 2011; Simoni, et al, 2011). However, sometimes it is present and undiagnosed. This may have played a role in the earlier discussion about vitality as an unexpected finding of how maternal factors affect family management of the child’s illness ability. As noted earlier, low vitality (i.e. low energy and fatigue) may be resultant when women use all of their energy on daily living and perhaps dealing with substance use or mental health issues. We suggest a further look at vitality and how this factor may influence family management.

We know that in some families there are more than just a mother and one child infected with HIV. In four cases in this study, there were two children who were HIV infected. For analysis in this study, the younger of the two HIV infected children were included in the analysis. The reason for this choice was that it was assumed that
younger children would require more care. Because the sample size was small, adding these four cases would have made the analysis complicated and would have required nesting which would most likely have not yielded reliable or useful results.

**Directions for Future Research and Conclusion**

The population of interest in this study was HIV infected mothers and their HIV infected children. We know that family constellation can be described in many ways and the number of families affected by chronic illness is large in the general population. This study is a beginning in understanding how child outcomes are affected when both a mother and child have HIV. This study showed that maternal factors (4 quality of life factors—bodily pain; general health; mental health, role-emotional; self-care and depression) were important to family management of the child’s illness and to child outcomes. Future studies are recommended to confirm these findings and to explore and to identify interventions to address maternal factors such as depression and quality of life and self-care. In adults, HIV disease is a viral illness that is transmitted by specific risk taking behaviors such as drug use and unprotected sexual encounters which are either associated with or the direct result of mental illness. Many of the women in this study had self-identified depression based on the CES-D scale. Ultimately, identifying and treating depression and mental health issues may prevent HIV infection and provide better outcomes for those infected (Vlassova, Angelino & Treisman, 2009). In families, this may become important to successful family management and better child outcomes.

Mothers and their children continue to experience health disparities. Racial inequalities exist and are persistent and pervasive in the onset, management courses and outcomes of illnesses (Williams, 2012). HIV is just one of an important number of diseases where racial and ethnic disparity persists. This is particularly concerning
because of the large, disparate numbers of persons of color affected by this disease (CDC, 2012). Racial and ethnic disparities are particularly alarming because of several factors, which continue to exist. Minorities get sick and die at younger ages, suffer racial inequality in the severity and progression of disease and experience stigmatization which affects perceived discrimination which can adversely affect health care access and utilization (Williams, 2012). This places an overarching need to consider the factors that place persons in situations of inequality (Williams, 2012). While all of the children in this sample received HIV related health care on a standard of care basis (usually every 3 months), the women in this study were not as engaged in HIV related health care. Thirteen women had not had a health care visit in the one year prior to participating in this study. Many did not disclose that they had not attended a visit to the study staff and this information was discovered in chart review or through release of records. It is very possible, and supported by the literature that these women experience health disparities based on race, ethnicity and gender and even geographic location despite the fact that they live in urban areas (El-Sadr, et al, 2010; Williams, 2012). Women living with HIV often delay entry into care and experience poor outcomes (Aziz & Smith, 2011) for various reasons including cultural beliefs about their illness, experienced stigma, fear of disclosure, fear of discrimination, and lack of insurance (Aziz & Smith, 2012; Wingood, et al, 2007).

Family life is dynamic and as such the cross-sectional design limited what is known about which factors may be contributing to child outcomes over time. A longitudinal design, along with an adequate sample size, may assist in identifying further maternal factors, which influence child outcomes as well as examine the potential mediating relationship of family management of the child’s illness factors. As a woman, caring for your own health care needs in the context of parenting is a complex issue. Having to
care for your child with chronic illness can also be complex. To design effective interventions, understanding which maternal factors affect family management and child outcomes are important.

This cross-sectional study examined mothers and their children, which places a limitation on analysis of the entire family who may be affected by HIV. Many families who have a mother and or child with a chronic condition, such as in this study, have additional family members affected by the same or different condition. Future research is needed to examine other family members over time to capture family health. Each family member has a unique perspective not only about their own health, but that of the others in the family. Alternate methods are needed that account for the intra-familial correlation (IFC) in outcome measurements members of the same family (Knafl, 2011).

This study identified that stigma, as a process external to the intra-family process must be considered in any interventions. This study has identified trends in maternal factors, which affect family management of the child’s illness and child clinical outcomes. This study is a beginning point for understanding intra-family processes in HIV infected mother and their HIV infected children. Further study is needed on the influence of family management on child clinical outcomes.
APPENDICES

Appendix A:
Table of Measures

Appendix B:
1994 Revised Classification System for Human Immunodeficiency Virus Infection in Children Less Than 13 Years of Age

CDC Classification System for HIV-Infected Adults and Adolescents

Appendix C:
Quantitative Measures for the Self-Care and Family Management of HIV Infected Women and Their HIV infected Children Study
## Appendix A
### Table of Measures

Summary of Instruments for Dissertation Study (name, author and year, brief description, # of items, Standardization sample; Subject burden/time to administer; special circumstances (can be read to subject, cultural sensitivity, cost, etc.))

### Quality of Life

<table>
<thead>
<tr>
<th>Name of Instrument</th>
<th>Author and Year</th>
<th>Brief Description</th>
<th>Domains and # of Items</th>
<th>Standardization Sample</th>
<th>Subject Burden, Time to Administer</th>
<th>Special Circumstances (i.e. administration mode, cost, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Outcome Survey SF-36 (MOS SF-36), Version 2.0 SF-36v2® Health Survey Ware, et al., 2000</td>
<td>Survey to measure quality of life including functional health and well-being from the patient's point of view. Generic measure for ages 18 years and older</td>
<td>Physical Health (physical functioning; role physical; bodily pain; general health and vitality) Mental Health (social functioning, role-emotional and mental health) Total of 36 items</td>
<td>Clinicians and patients in three large U.S. census areas: Los Angeles, Boston, Chicago who were English speaking and 18 years of age or greater. Data was taken from the Medical Outcomes Survey. The patient sample completed a 245-item baseline questionnaire, which were used to construct the SF-36 (n=3,445). Patients then completed a health examination within one month.</td>
<td>5-10 minutes</td>
<td>Self administration or interviewer administered; paper and pencil or computer administration; Standard 1 vs. 4 week recall Version 2 uses Tscores (mean 50; standard deviation 10) Norm based scoring Sum Scores and Domain scores Flesch-Kincaid reading level: 6.9 Cost is different for student vs. funded researcher or clinical area. Translated into 120 languages</td>
<td></td>
</tr>
</tbody>
</table>

### Depression

<table>
<thead>
<tr>
<th>Name of Instrument</th>
<th>Author and Year</th>
<th>Brief Description</th>
<th>Domains and # of Items</th>
<th>Standardization Sample</th>
<th>Subject Burden, Time to Administer</th>
<th>Special Circumstances (i.e. administration mode, cost, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Center for Epidemiologic Studies-Depression (CES-D) (Radloff, 1977)</td>
<td>The CES-D scale is designed to measure depressive symptoms in the general population ages 18 and older.</td>
<td>20 item scale measures the major components of depressive symptomatology, including depressive mood, feelings of guilt and worthlessness, psychomotor retardation, loss of appetite, and sleep disturbance.</td>
<td>Probability sample of households representative of two communities of persons 18 years and older A psychiatric patient sample was done for clinical validation.</td>
<td>10 minutes</td>
<td>Self administered Recall over the last week Flesch-Kincaid reading level: 4.1 Translated into 40 languages. Cost is free</td>
<td></td>
</tr>
<tr>
<td>Name of Instrument</td>
<td>Author and Year</td>
<td>Brief Description</td>
<td>Domains and # of Items</td>
<td>Standardization Sample</td>
<td>Subject Burden, Time to Administer</td>
<td>Special Circumstances (i.e. administration mode, cost, etc.)</td>
</tr>
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<td>--------------------</td>
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</tbody>
</table>
| Parental Self Care Scale | (Abell, Ryan & Kamata, 2006) | Survey designed to assess the parent’s belief that they can care for themselves while maintaining their parenting/household responsibilities using the conceptual underpinnings of self-efficacy and self-management | One sum score and three sub scale scores (emotional, instrumental and nursing) 20 items | 161 clients of two HIV/AIDS family services agencies in Los Angeles and Boston responded to the Parental self care survey. (72 Spanish speaking and 89 English speaking with 93% HIV positive and 84.5% female). | 5-10 minutes | Self or Interviewer administration  
Available in English and Spanish  
Flesch-Kincaid reading level: 9.5  
Cost is Free |
<table>
<thead>
<tr>
<th><strong>Family Management</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name of Instrument</strong></td>
</tr>
<tr>
<td><strong>Author and Year</strong></td>
</tr>
<tr>
<td><strong>Brief Description</strong></td>
</tr>
<tr>
<td><strong>Domains and # of Items</strong></td>
</tr>
<tr>
<td><strong>Standardization Sample</strong></td>
</tr>
<tr>
<td><strong>Subject Burden,</strong></td>
</tr>
<tr>
<td><strong>Time to Administer</strong></td>
</tr>
<tr>
<td><strong>Special Circumstances</strong></td>
</tr>
<tr>
<td><strong>(i.e. administration mode, cost, etc.)</strong></td>
</tr>
<tr>
<td><strong>Family Management Measure (FaMM)</strong></td>
</tr>
<tr>
<td>(Knafl, Deatrick, Gallo, Dixon, &amp; Grey (in press))</td>
</tr>
<tr>
<td>The FaMM survey is intended to measure how families manage caring for a child with a chronic condition/illness and the extent to which they incorporate condition management into everyday family life. The survey measures key aspects of family management, which will lead to a more precise understanding of factors that support or impede optimal child and family functioning.</td>
</tr>
<tr>
<td>FaMM has 53 items (45 items for all parents and 8 additional items for partnered parents only. Five summated scales for all parents measuring: Child's Daily Life, Condition Ability, Condition Management Effort, Family Life Difficulty, and View of Condition Impact. Sixth scale for partnered parents measuring Parental Mutuality. Higher scores on Child's Daily Life, Condition Management Ability, and Parental Mutuality) indicate greater ease in managing the child's condition. Higher scores on other three scales (Condition Management Effort, Family Life Difficulty, and View of Condition Impact) indicate greater difficulty in managing the condition. Dissertation applied 3 scales: Condition Management Ability Scale (12 items) Family Life Difficulty Scale (14 items) Condition Management Effort Scale (4 items)</td>
</tr>
<tr>
<td>579 parents (65 single mothers; 11% minority participation)</td>
</tr>
<tr>
<td>10 minutes</td>
</tr>
<tr>
<td>Available in English</td>
</tr>
<tr>
<td>Self administration</td>
</tr>
<tr>
<td>Flesch-Kincaid reading level: 8.1</td>
</tr>
<tr>
<td>Cost is free</td>
</tr>
<tr>
<td>Name of Instrument</td>
</tr>
<tr>
<td>--------------------</td>
</tr>
<tr>
<td>Berger HIV Stigma Scale © (Berger, 2006)</td>
</tr>
</tbody>
</table>
Appendix B

1994 Revised Classification System for Human Immunodeficiency Virus Infection in Children Less Than 13 Years of Age

Pediatric human immunodeficiency virus (HIV) classification *

<table>
<thead>
<tr>
<th>Immunologic categories</th>
<th>N: No signs/symptoms</th>
<th>A: Mild signs/symptoms</th>
<th>B: + Moderate signs/symptoms</th>
<th>C: + Severe signs/symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: No evidence of suppression</td>
<td>N1</td>
<td>A1</td>
<td>B1</td>
<td>C1</td>
</tr>
<tr>
<td>2: Evidence of moderate suppression</td>
<td>N2</td>
<td>A2</td>
<td>B2</td>
<td>C2</td>
</tr>
<tr>
<td>3: Severe suppression</td>
<td>N3</td>
<td>A3</td>
<td>B3</td>
<td>C3</td>
</tr>
</tbody>
</table>

* Children whose HIV infection status is not confirmed are classified by using the above grid with a letter E (for perinatally exposed) placed before the appropriate classification code (e.g., EN2).

+ Both Category C and lymphoid interstitial pneumonitis in Category B are reportable to state and local health departments as acquired immunodeficiency syndrome.

CDC, 2012d

CDC Classification System for HIV-Infected Adults and Adolescents

<table>
<thead>
<tr>
<th>CD4 Cell Categories</th>
<th>Clinical Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Abbreviations:</strong> PGL = persistent generalized lymphadenopathy</td>
<td>A</td>
</tr>
<tr>
<td>(1) ≥500 cells/µL</td>
<td>Asymptomatic, Acute HIV, or PGL</td>
</tr>
<tr>
<td>(2) 200-499 cells/µL</td>
<td>Symptomatic Conditions, not A or C</td>
</tr>
<tr>
<td>(3) &lt;200 cells/µL</td>
<td>AIDS-Indicator Conditions</td>
</tr>
</tbody>
</table>

CDC, 2012e
### Appendix C

Quantitative Measures for the Self-Care and Family Management of HIV Infected Women and Their HIV infected Children Study

<table>
<thead>
<tr>
<th>Measure name</th>
<th>n</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Score interpretation</th>
<th>Literature Mean/SD</th>
<th>α</th>
<th>Skewness</th>
<th>Standard error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life (SF-36v2®)</td>
<td>8 domains</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>T score measures range from 0-100 All 8 Quality of Life domains use T scores **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>6 7</td>
<td>14.9</td>
<td>4</td>
<td>57.0</td>
<td>3</td>
<td>47.1</td>
<td>1</td>
<td>11.43</td>
<td>Low scores indicate significant limitations in physical functioning</td>
<td>32.17±30.8</td>
</tr>
<tr>
<td>Role-physical</td>
<td>6 7</td>
<td>17</td>
<td>85</td>
<td>46.1</td>
<td>1</td>
<td>11.39</td>
<td>Low scores indicate problems with work as a result of physical problems</td>
<td>33.05±39.4</td>
<td>3</td>
<td>N</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>6 7</td>
<td>19.8</td>
<td>6</td>
<td>62.1</td>
<td>2</td>
<td>45.2</td>
<td>0</td>
<td>11.73</td>
<td>Low scores indicate high levels of pain that impact normal activities.</td>
<td>50.77±28.8</td>
</tr>
<tr>
<td>General Health</td>
<td>6 7</td>
<td>18.6</td>
<td>1</td>
<td>63.9</td>
<td>0</td>
<td>45.0</td>
<td>0</td>
<td>11.35</td>
<td>Low scores indicate evaluation of general health as poor and likely to get worse.</td>
<td>40.81±24.0</td>
</tr>
<tr>
<td>Vitality</td>
<td>6 7</td>
<td>20.8</td>
<td>7</td>
<td>70.8</td>
<td>2</td>
<td>48.5</td>
<td>9</td>
<td>11.14</td>
<td>Low scores indicate evaluation of feelings of tiredness and being worn out.</td>
<td>31.84±20.9</td>
</tr>
<tr>
<td>Social functioning</td>
<td>6 7</td>
<td>13.2</td>
<td>2</td>
<td>56.8</td>
<td>5</td>
<td>43.7</td>
<td>4</td>
<td>11.32</td>
<td>The lowest scores equate to extreme or frequent interference with normal social activities due to physical and emotional problems.</td>
<td>56.97±30.6</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>6 7</td>
<td>9.23</td>
<td>8</td>
<td>55.8</td>
<td>8</td>
<td>42.8</td>
<td>8</td>
<td>13.78</td>
<td>Low scores on this scale reflect problems with work or other activities as a result of emotional problems.</td>
<td>54.29±45.8</td>
</tr>
<tr>
<td>Mental Health</td>
<td>6 7</td>
<td>16.2</td>
<td>2</td>
<td>64.0</td>
<td>9</td>
<td>43.8</td>
<td>3</td>
<td>13.33</td>
<td>Low scores indicate frequent feelings of nervousness and depression.</td>
<td>61.62±20.7</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>7</td>
<td>2.65</td>
<td>10</td>
<td>8.01</td>
<td>1.92</td>
<td>High scores indicate higher capacity for self-care</td>
<td>3.79±.9</td>
<td>.95</td>
<td>-.900</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---</td>
<td>---</td>
<td>------</td>
<td>----</td>
<td>------</td>
<td>------</td>
<td>-------------------------------------------------</td>
<td>----------</td>
<td>----</td>
<td>-------</td>
</tr>
<tr>
<td>CES-D (depression)</td>
<td>6</td>
<td>7</td>
<td>0</td>
<td>51</td>
<td>19.9</td>
<td>13.23</td>
<td>Scores greater than 16 indicate greater risk for depressive symptomatology</td>
<td>27.9±12.7</td>
<td>.93</td>
<td>.448</td>
</tr>
<tr>
<td>Family Management (FaMM)</td>
<td>6</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Condition management ability</td>
<td>6</td>
<td>7</td>
<td>31</td>
<td>59</td>
<td>46.7</td>
<td>6.91</td>
<td>Higher scores indicated the condition was viewed as more readily manageable</td>
<td>49.3±6.3</td>
<td>.65</td>
<td>-.409</td>
</tr>
<tr>
<td>Family life difficulty</td>
<td>6</td>
<td>7</td>
<td>14</td>
<td>58</td>
<td>27.9</td>
<td>10.56</td>
<td>Higher scores indicated more difficulty in managing the condition</td>
<td>30.80±11.4</td>
<td>.83</td>
<td>.799</td>
</tr>
<tr>
<td>Condition management effort</td>
<td>6</td>
<td>7</td>
<td>4</td>
<td>20</td>
<td>11.1</td>
<td>3.72</td>
<td>Higher scores indicated more effort is expended in managing the illness</td>
<td>13.50±4.2</td>
<td>.38</td>
<td>.260</td>
</tr>
<tr>
<td>Maternal HIV viral load</td>
<td>6</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>1.67</td>
<td>0.47</td>
<td>1=undetectable HIV viral load 2=detectable HIV viral load Transformed continuous data to categorical variable based on clinical interpretation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child CD4 count</td>
<td>6</td>
<td>7</td>
<td>1</td>
<td>3</td>
<td>1.24</td>
<td>.50</td>
<td>1=mild immunosuppression 2=moderate immunosuppression 3=severe immunosuppression Transformed continuous data to categorical variable based on clinical interpretation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child HIV viral load</td>
<td>6</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>1.45</td>
<td>.50</td>
<td>1=undetectable HIV viral load 2=detectable HIV viral load Transformed continuous data to categorical variable based on clinical interpretation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Berger Stigma Scale</td>
<td>6</td>
<td>5</td>
<td>19</td>
<td>70</td>
<td>42.6</td>
<td>9</td>
<td>12.33</td>
<td>Higher scores indicate the individual perceives internalized stigma</td>
<td>No comparative data</td>
<td>.94</td>
</tr>
<tr>
<td>---------------------</td>
<td>---</td>
<td>---</td>
<td>----</td>
<td>----</td>
<td>------</td>
<td>---</td>
<td>-------</td>
<td>-------------------------------------------------</td>
<td>-----------------</td>
<td>-----</td>
</tr>
<tr>
<td>Personalized stigma</td>
<td>6</td>
<td>5</td>
<td>15</td>
<td>40</td>
<td>31.6</td>
<td>5</td>
<td>5.02</td>
<td>Higher scores indicate a perception of concern if HIV is disclosed.</td>
<td>No comparative data</td>
<td>.76</td>
</tr>
<tr>
<td>Disclosure</td>
<td>6</td>
<td>5</td>
<td>13</td>
<td>46</td>
<td>31.8</td>
<td>2</td>
<td>7.85</td>
<td>Higher scores indicate the individual with HIV perceives a negative self-image</td>
<td>No comparative data</td>
<td>.85</td>
</tr>
<tr>
<td>Negative self-image</td>
<td>6</td>
<td>5</td>
<td>22</td>
<td>80</td>
<td>53.0</td>
<td>2</td>
<td>11.39</td>
<td>Higher scores indicate public attitudes toward the individual with HIV are perceived as negative.</td>
<td>No comparative data</td>
<td>.92</td>
</tr>
</tbody>
</table>

* normed measure

** Information taken from Table 2 Summary Descriptions of SF-36 Version 2® Health Survey Domains
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