Title
BECOMING A MOTHER WITHIN THE CONTEXT OF HIV: EXPERIENCES OF UNCERTAINTY, DISTRESS AND SOCIAL SUPPORT DURING THE HIV VIRAL TESTING OF THE INFANTS

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Becoming a Mother Within the Context of HIV: Experiences of Uncertainty, Distress, and Social Support During HIV Viral Testing of the Infant

by

Maureen Theresa Shannon

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
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by

Maureen Theresa Shannon

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Dedication

To the HIV-infected women who generously agreed to participate in this study and who continue to teach and inspire me to do this work.

To my grandparents who encouraged me to pursue my education so I would be able to help others.

To my husband, Bob Pantell, and our children, Matthew, Gregory and Megan:

Thank you for all of your encouragement, wisdom, laughter and love during this long journey.
Acknowledgements

The pursuit of my doctoral degree was not a journey I started in isolation and is one that has been successful because of those who have traveled this path with me. All of these individuals deserve recognition and thanks for their unique and unwavering support of me throughout this process.

First, this research project would never have been started without the input I received as a clinician from HIV-infected mothers coming into the clinic to have their infants tested. Listening to them inspired me to question and seek answers about the process of becoming a mother within the context of HIV infection. I am very grateful to the women who graciously agreed to participate in this study, giving up their time and sharing intimate details about their lives in order to expand our knowledge about and improve our care of HIV-infected mothers.

I also would not have been able to investigate important variables in this research project without having access to instruments developed by nursing scholars whose work laid the foundation for my doctoral research. Dr. Sheila Santacroce (author of the Parental Perceptions of Uncertainty Scale – Diagnosis) and Dr. Virginia Tilden (author of the Interpersonal Relationship Inventory) both graciously allowed me to use their instruments in this study. Without access to these instruments, major findings of this study may not have been determined.

The first mentor that I had at the University of California, San Francisco School of Nursing was Dr. Ramona Mercer. During my graduate studies in the Master of Science in Nursing program she inspired me to identify gaps in our understanding of the process of “becoming” parents. Her guidance extended beyond simply teaching the
theoretical concepts and current scientific evidence about becoming a parent to that of being a true mentor. She assisted me with my first attempts at conducting independent research – the experiences of fathers during the birthing process of their partners. Her encouragement resulted in the completion of my first research study and my first publication. I know that I would never have accomplished either of those without her encouragement and direction. I am grateful to Dr. Mercer for her recognition of my potential to become a nurse scientist, and for being an incredible example to me of what defines a true mentor and nursing leader.

My Doctoral Committee members have steadfastly guided me through the highs and lows of my doctoral studies, research, grant writing, and preparation of papers for publication. Dr. Kathy Lee has been my mentor from the very beginning and has wisely advised me throughout this process and provided me with enthusiastic support – even when I doubted my abilities to conduct a complicated dissertation study. Dr. Holly Powell Kennedy afforded me opportunities to enhance my understanding of qualitative methods and participate in the preparation of articles that were published in a number of journals. She also counseled me about my future research and academic professional opportunities. Dr. Janice Humphreys encouraged me to pursue new conceptual frameworks for understanding and researching traumatic life events in vulnerable women, and collaborated on papers that incorporate these issues. Dr. Ruth Greenblatt has long been an inspirational role model for me, providing an example of the ways I can integrate my clinical, academic and research interests. Through her example and mentorship I am continually reminded that the purpose of my research is to assist clinicians in their provision of care to HIV-infected women and their families.
Tedious hours hunched over statistics problems, data entry and analysis, and the seemingly endless writing of papers and grants would have been intolerable without the support and humor of my fellow doctoral students, especially those who started this process with me in September 2001. I have to offer a huge “thank you” to Anne Hughes (my doctoral program “doula”), Catherine Dodd, and Ruth Taylor-Piliae who kept my spirits up when the work seemed incredibly overwhelming. Their perspectives on life as doctoral students, their jokes and words of encouragement, and their acts of kindness during this process reinforced my commitment to obtain my PhD.

I wish to acknowledge the financial support that I received: the National Research Service Award #F31-NR008181 from the National Institute of Nursing Research and the National Institutes of Health; the 2005 Woodrow Wilson and Johnson and Johnson Foundation Dissertation Award in Women’s Health; and the dissertation grant #D05-SF-403 from the California Universitywide AIDS Research Program. Each of these awards allowed me protected time so I could complete my doctoral studies and research.

Finally, but most importantly, I owe a great deal of gratitude to my family. My grandparents were instrumental in my becoming a nurse and continuing my education in order to enhance the clinical care of patients. My husband, Bob, and our children Matthew, Gregory and Megan, all participated in my decision to proceed with my doctorate, realizing that significant adjustments in their lives would be necessary if I were to succeed. Despite several of their own personal challenges, they have continued to support me throughout this journey – especially whenever I doubted my ability to be successful in this endeavor. The warmth and reassurance of their smiles and laughter
kept me going. My hope is that their support will continue as I proceed with my
nursing career.

Maureen Shannon, CNM, FNP, MS (June 2007)

Approval of Dissertation Committee Chair

The text of this dissertation contains a reprint of published material entitled
“Allostasis: A theoretical framework for understanding and evaluating perinatal health
outcomes” as it appears in *JOGNN. Journal of Obstetric, Gynecologic and Neonatal
Nursing*. Blackwell Publishing granted permission to reprint the entire article as a
chapter for the dissertation. The student, Maureen Shannon, was responsible for more
than 90% of the work involved for the completion of the article including the review of
the scientific literature, conceptual synthesis, and writing of the manuscript. The co-
authors listed in this publication directed and supervised the review and research that
forms the basis for this chapter of the dissertation. The work is comparable with a
chapter representing the literature review in a standard dissertation. Two other chapters
entitled “HIV-infected mothers’ foci of concern during the HIV viral testing of their
infants” and “Perceptions of uncertainty, stress, distress and social support in HIV-
infected mothers during the HIV viral testing of their infants” will be submitted for
publication. These papers represent research and scholarship comparable in scope and
contribution to chapters addressing methods and findings in a standard dissertation.

\[Signature\]

Kathryn A. Lee, RN, PhD, FAAN
Dissertation Committee Chair
The purpose of this prospective, longitudinal repeated measures study was to explore the relationships between HIV-infected mothers’ perceptions of uncertainty about infant HIV serostatus and maternal stress, distress, and social support during the infants’ HIV viral testing. HIV-infected women were eligible to participate if they were at least 18 years old, English speaking, and were the primary caretaker for their infants. Six study visits were required: a visit during the third trimester of pregnancy and 5 postpartum visits clustered around infants’ second and final HIV viral testing. Data collection included maternal and infant demographics, clinical variables, standardized questionnaires, and maternal responses to questions addressing their most worrisome concern. During the final study visit, maternal interviews about their infants’ HIV testing were audiotaped and transcribed. Descriptive statistics, Pearson’s $r$, and RMANOVA were used to analyze quantitative data; qualitative methods were used to analyze interviews.

Twenty mothers enrolled: 40% African American, 40% white, 10% Hispanic, 10% Native American/Other; mean age = 32.25 years; mean education = 14.5 years. All infants in the study were determined to be HIV negative. Mothers were most concerned
about infant health during the prenatal and early postpartum period. While infant
concerns diminished after the second negative HIV test they rebounded prior to
obtaining the final viral test. Family and psychosocial issues were the primary maternal
concerns after infant viral testing was completed. Maternal health issues never
surpassed infant or psychosocial issues as a primary concern. There was a significant
decrease in maternal uncertainty about infant HIV serostatus over time ($p<.001$).
Mothers with depressive symptoms (50%) demonstrated significantly more uncertainty
after receiving results for the second viral test ($p=.03$). There was a strong inverse
correlation between social support and uncertainty ($r = -.67, p<.001$), stress ($r = -.79,
p<.001$), distress ($r = -.65, p<.01$), and depression ($r = -.68, p<.001$). Maternal
uncertainty about infant health declined significantly over time. Once infant viral
testing was completed, mothers focused on issues other than their own health.
Increased social support and other clinical interventions may reduce the uncertainty,
stress, and distress HIV-infected mothers experience during infant HIV viral testing.

Word Count: 349

Approved:

Kathryn A. Lee, RN, Ph.D, FAAN
Dissertation Chairperson
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Chapter 1.

Introduction
The first cases of acquired immune deficiency syndrome (AIDS) in the United States (U.S.) were reported to the Centers for Disease Control and Prevention (CDC) in 1981 (CDC, 1981). The reports described a rare type of pneumonia (*Pneumocystis carinii pneumonia*) in young homosexual men who were without evidence of other causes for severe immune dysfunction (CDC, 1981). Shortly after these reports, the first cases of AIDS in women and infants were documented (CDC, 1982; CDC, 1983). The scientific response to these events resulted in a tremendous expansion of our knowledge about the pathology, prevention, and medical treatment of HIV infection. However, despite our knowledge and efforts, 39.5 million people worldwide are currently infected with HIV (World Health Organization [WHO], 2006). Nearly half of these infections have occurred in women, the majority of whom are of reproductive age (WHO, 2006).

Although HIV infection is now regarded as a manageable chronic disease, especially in countries where patients have access to antiretroviral (ARV) and opportunistic infection prophylactic medications, living with HIV disease involves considerable challenges. Persons diagnosed with HIV must incorporate lifestyle changes to improve their health and prevent transmission to others (e.g., strict adherence to ARV medications, engaging in safer sex methods), manage toxicities associated with ARV medications, and deal with psychosocial issues relatively common to this disease (e.g., stigma, fear of disclosure). A major dilemma many HIV-infected women face is whether or not to become pregnant because of the risk of mother-to-child-transmission (MTCT).
For over a decade, research strategies to prevent MTCT of HIV have had significant positive results. In resource rich countries, MTCT rates have declined from 25% to less than 2% primarily due to the use of highly active antiretroviral therapy (HAART), the administration of neonatal antiretroviral prophylaxis, and formula feeding of perinatally-exposed infants (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006). Consequently, HIV-infected women who choose to become mothers are expected to give birth to healthy, uninfected infants. However, for HIV-infected childbearing women, transitioning to a maternal role differs substantially from non-infected women. In addition to managing their own HIV disease and medications they must deal with the administration of prophylactic antiretroviral medication several times a day to their infants and make sure that complex diagnostic testing of their infants is completed to definitively ascertain the presence or absence of HIV infection. Early in the epidemic, perinatally-exposed infants had to undergo HIV antibody testing to document the loss of maternal IgG antibodies that are transplacentally transferred during pregnancy. This process delayed the determination of an infant’s HIV status for at least 18 months after birth. Currently, the use of HIV DNA and RNA polymerase chain reaction (PCR) viral testing can shorten the interval required to diagnose HIV infection in infants. At least 99% of HIV infected infants are diagnosed after three sequential tests are performed during the first 4 to 6 months after birth (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006). The use of these viral assays to determine HIV infection status earlier in an infant’s life can be reassuring. However, although each negative test
reduces the likelihood an infant is infected, some mothers may continue to experience worry and uncertainty during this process.

Previous research investigating motherhood within the context of HIV infection provides a foundation for understanding the lived experiences of infected mothers as they attempt to cope with care-taking responsibilities for their infants, especially while awaiting confirmation of the infant’s HIV infection status. However, the majority of published studies have used cross-sectional designs, included cohorts of infected women who gave birth prior to the use of HAART to reduce MTCT, and were completed prior to the routine use of PCR HIV viral testing to diagnose infection in exposed infants. In addition, none of the studies evaluated maternal experiences during the first three months postpartum, and only one study (Santacroce, 2000) specifically investigated maternal perceptions of uncertainty about infant HIV serostatus during the first 18 months after birth.

Parental uncertainty or misunderstanding about the health status of an infant or child has been documented to contribute to parental psychological distress (e.g., anxiety, depression, posttraumatic stress syndrome), aberrant maternal-infant relationships, and the development of the vulnerable child syndrome (Moses-Kolko & Roth, 2004; Pearson & Boyce, 2004; Stewart & Mishel, 2000). The complexities involved with the HIV viral testing of perinatally-exposed infants, the discomfort associated with the physical process of obtaining the sample from the infant, and the length of time required to receive each result (approximately 7 days) may contribute to maternal stress and distress. Maternal psychological distress may be compounded by the guilt that mothers may experience for having placed their infants at risk for HIV
Experiences of chronic stress and distress in infected mothers have the potential to interfere with their own health care, particularly adherence to medical appointments and antiretroviral medications. Furthermore, in an attempt to cope with perceptions of stress and distress, HIV-infected mothers may engage in unhealthy behaviors (e.g., alcohol consumption, smoking) that can contribute to immune deterioration and place them at risk for both HIV and non-HIV-related morbidities.

The purpose of this dissertation project was to use qualitative and quantitative methods to explore HIV-infected mothers’ perceptions of uncertainty, stress, distress, and social support during the HIV viral testing of their infants. This dissertation consists of five chapters: an introductory chapter; chapters 2, 3 and 4 that are separate papers that have been prepared for submission for publication; and a final chapter.

The second chapter is entitled: “Allostasis: A theoretical framework for understanding and evaluating perinatal health outcomes” and is a paper that has been published. The content of this chapter is a reprint of material that appears in (Shannon, King, Kennedy), *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, Volume 36, Number 2, pages 125-134. The first author was responsible for more than 90% of the review of the literature for this paper as well as the writing of the text. The paper is a review of the theory of allostasis and how it may provide a basis to better understand the relationship between physiological and psychological stress and distress and adverse perinatal health outcomes, some of which (e.g., pre-eclampsia, preterm birth) have been
documented to occur more frequently in some HIV-infected pregnant women (Suy et al., 2006).

The third chapter is entitled: “HIV-infected mothers’ foci of concern during the HIV viral testing of their infants”. The purpose of this paper is to present findings about HIV-infected mothers’ most worrisome concerns during the HIV diagnostic testing of their infants. Content analysis was used to categorize concerns identified by twenty mothers during study visits conducted at six time points: once during the third trimester of pregnancy and five times after delivery to coincide with infant HIV viral testing.

The fourth chapter is entitled: “Perceptions of uncertainty, stress, distress and social support in HIV-infected mothers during HIV viral testing of their infants”. This paper describes the results of a longitudinal, prospective, repeated measures study using standardized instruments to determine perceptions of uncertainty about infant HIV infection, stress, psychological distress and social support in twenty HIV-infected mothers during the HIV viral testing of their infants. The study time points are the same as those used for the qualitative study investigating maternal foci of concern.

The final chapter summarizes and synthesizes the findings of chapters 2, 3, and 4 and provides suggestions for future research based on the results from this dissertation project.
Chapter 2.

Allostasis: A Theoretical Framework for Understanding and Evaluating Perinatal Health Outcomes

Abstract

Objective: The objective of this review was to explore the theory of allostasis within the context of childbearing women’s perceptions or experiences of stress and perinatal health outcomes.

Data Sources: The literature review included articles published in refereed journals, as well as selected chapters from published books that addressed physiologic and psychologic effects of perceived or actual stress experiences, including the theory of allostasis, on health outcomes.

Study Selection: Review of the literature included qualitative, quantitative, and review articles that focused on psychoneurohormonal responses to physical and psychological stress in pregnant and non-pregnant human cohorts, and the theory of allostasis.

Data Extraction and Synthesis: The impact of abnormal allostatic states in childbearing women in response to physiological and psychological perceptions and/or experiences of stress was analyzed. There is a growing body of epidemiologic evidence to support the relationship between maternal stress and adverse pregnancy outcomes.

Conclusion: The theory of allostasis provides a framework for understanding and evaluating the complex elements of stress, coping, and adaptation during childbearing on perinatal health outcomes and has the potential to provide new insight into previously unexplained adverse perinatal events.

Key Words: Allostsis, allostatic states, childbearing, infant health, maternal health, perinatal outcomes, pregnancy, stress
Introduction

For most women, pregnancy is a normal psychological and physiological process that results in the birth of a healthy infant and the establishment of a sound maternal-infant relationship. However, childbearing can be associated with adverse psychological and physiological events that threaten the health of both the mother and fetus/infant. In some instances, pre-existing maternal conditions contribute to the increased risk of childbearing and neonatal complications. Conversely, the absence of pre-existing conditions in women prior to conception does not protect them from developing pregnancy-related complications (e.g., pre-eclampsia). This dichotomy suggests that there are complex dimensions of the perinatal process that are not yet understood. In particular, the relationship between physiological and psychological factors and perinatal health outcomes needs further elucidation.

Allostasis is a concept that describes the relationship between psychoneurohormonal responses to stress and physical and psychological manifestations of health and illness (McEwen, 1998). The theory of allostasis provides a new approach to assessing perinatal health. The purpose of this article is to summarize current concepts about the relationship between stress and pregnancy and provide an overview of the possible contribution to the field by allostasis theory, its relationship to maternal and fetal stress and perinatal health outcomes, and clinical interventions that target improving health from the perspective of this theoretical framework.

Sources of Information
Searches of PUBMED and CINAHL databases were conducted using keywords that included “allostasis”, “allostatic load”, “human stress response”, “stress (acute, chronic, psychologic, physiologic)”, “distress (acute, chronic)”, “perinatal stress”, “maternal stress”, “perinatal complications”, “fetal stress”, “normal pregnancy and stress”, “obstetrical complications and stress”, “stress aging”, “stress hormones and pregnancy”, “life course theory”, “social support and stress”, “weathering”, and “maternal and infant relationships”. Review articles and qualitative and quantitative research reports that focused on physical and psychological stress in non-pregnant and pregnant human cohorts and theoretical and conceptual frameworks about stress and stress responses published in refereed journals were included in the review for this paper.

Review of the Literature

Definitions

The terms “stress” and “distress” are often used interchangeably; however, they are different concepts. For the purposes of this review, the term “stress” refers to perceptions or actual experiences of environmental demands (either internal or external) that tax or exceed an individual’s ability to cope (Lazarus & Folkman, 1984). Perceptions of stress may result in several health outcomes that include a beneficial effect, a deleterious effect, or no effect depending on a number of complex factors (McEwen, 1998). “Distress” refers to an individual’s psychological or physiological response to stress that result in disharmony or threatened homeostasis (Cohen &
Williamson, 1988; McEwen, 2005). “Coping” is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141).

**Normal Human Response to Stress (Non-pregnant cohorts)**

The normal physiologic response to stress involves complex, dynamic feedback mechanisms between neuroendocrine, cardiovascular, metabolic, and immune systems (McEwen, 1998). Stimulation of the hypothalamic-pituitary-adrenal (HPA) axis occurs in response to perceptions or experiences of physically or psychologically stressful stimuli. The subsequent release of corticotropin-releasing hormone (CRH) by the hypothalamus stimulates the central autonomic-arousal system to release catecholamines (e.g., norepinephrine [NE]) from the adrenal medulla and the sympathetic nerve terminals, and adrenocorticosteroid hormone (ACTH) from the pituitary gland, which stimulates glucocorticoid (cortisol) release from the adrenal cortex (Sternberg, 1997). This cascade of events leads to adaptive responses that have behavioral, cardiovascular and metabolic, and immune components. The behavioral component results in improved alertness and attention, decreased reflex time, and diminished desire for eating and sexual activity. The cardiovascular and metabolic components (e.g., increased heart rate and blood pressure, conversion of glycogen stores to glucose) results in delivery of additional oxygen and nutrients to tissues that are needed to support the "fight or flight" response (Cacioppo et al., 1998; Sternberg, 1997). Under the influence of catecholamines and glucocorticoids, immune cells are
transported to parts of the body where they may be needed to fight infections or take part in other immune responses (McEwen, 1998). Feedback mechanisms serve to terminate adaptive responses when the stressful event has ceased.

Normal Alterations in Stress Responses During Pregnancy

The normal pregnant state induces physiological alterations in stress mediating hormones (Table 2.1). During the second and third trimesters increased levels of CRH are found in maternal plasma. Up to a four-fold increase in ACTH concentrations and an increase in bound and free cortisol are observed during gestation (Erickson et al., 2001; Nader, 2004). Although diurnal variation in the concentrations of these hormones during pregnancy is preserved, this variation is somewhat blunted compared to non-pregnant states. In addition, CRH production in the placenta is increased under the influence of glucocorticoids secreted by maternal adrenal glands (Erickson et al., 2001; Nader, 2004). In normal pregnancy the effect of glucocorticoids on CRH production is dose-related (Nader, 2004; Schulkin, 1999). Finally, a rapid decline of stress hormones to pre-pregnancy levels is observed within one to four days after birth (Erickson et al., 2001; Mastorakos & Ilias, 2003).

As early as 12 weeks gestation, CRH can be detected in the fetal hypothalamus produced primarily by the placenta. Fetal plasma concentrations of CRH are approximately 50% lower than maternal plasma levels. Adrenocorticosteroid hormone can also be detected in fetal plasma at 12 weeks gestation, with levels continuing to increase until approximately 34 to 35 weeks when a significant decline is observed (Mastorakos & Ilias, 2003). The majority of cortisol present in a fetus is maternal in
origin. Cortisol is also synthesized in the fetal adrenals by converting progesterone from the placenta. In addition, some fetal cortisol is supplied by the amniotic fluid after the conversion of cortisone to cortisol by the choriodecidua (Mastorakos & Ilias, 2003).

Health Outcomes Associated with Abnormal Responses to Stress

Non-Pregnant Human Cohorts

The hormone fluctuations during stress are responsive and usually self-limited; however, they can go awry in certain situations. Several studies conducted in healthy adults and children have demonstrated alterations in stress mediators (e.g., ACTH, cortisol, CRH) in response to acute and chronic stress. These alterations are associated with diminished immune activity (e.g., decreases in CD4+ lymphocyte cell percentage [Matthews et al., 1995], blunted antibody responses to immunizations [Marsland, Cohen, Rabin & Manuck, 2001], and increased rates of upper respiratory infections [Boyce et al., 1993; Boyce et al., 1995]). In addition, the expression and regulation of some stress mediators have been shown to be altered by negative mood states and traits (e.g., depression, anxiety, fear) (Miller, Cohen & Herbert, 1999; van Eck, Berkhof, Nicolson & Sulon, 1996), exposure to early-life stress (e.g., childhood physical or sexual abuse) (Heim et al., 2000), chronic stress (Matthews, Gump & Owens, 2001; Pruessner, Hellhammer & Kirschbaum, 1999) and low or unstable socioeconomic status (Seeman & McEwen, 1996). These alterations can adversely affect an individual’s responses to psychological and social stress resulting in the development of pathophysiological conditions such as bone demineralization (Michelson et al., 1996),
atherosclerosis and cardiovascular disease (McEwen, 1998), and cognitive impairment (Seeman, McEwen, Rowe & Singer, 2001).

It has been postulated that such pathological processes reflect the “wear and tear” an individual experiences from cumulative perceptions or experiences of stress (Hogue & Bremner, 2005). It is further hypothesized that individuals with these experiences are physiologically older than their chronological age (i.e., “stress aging”) and, therefore, are at an increased risk for developing pre-morbid conditions (e.g., central body fat deposition), actual disease states (e.g., diabetes mellitus) and/or premature death (Epel et al., 2000).

Epel and colleagues (2004) investigated the effects of chronic stress on telomere length in mothers who were caring for their chronically ill children. Telomeres are DNA-protein complexes that cap the ends of chromosomes, thereby promoting chromosomal stability and preventing chromosomal degradation (Epel et al., 2004; Mosquera et al., 1999). Normally, telomere length shortens in all human somatic cells with aging. As a result, telomere length can be used as a biomarker for evidence of aging. After controlling for maternal age and body mass index, Epel et al. (2004) found a significant ($p<0.05$) shortening of telomere lengths in the peripheral blood cells of the mothers in their cohort who reported experiencing high levels of chronic stress. The telomere length shortening in these mothers indicated at least ten years of additional aging compared to the mothers reporting perceptions of low stress. This finding lends support to the concept of stress aging and the possibility of prematurely developing life-threatening conditions earlier than would be anticipated by a person’s chronological age.
Perceptions of low social status and limited access to or use of available social support are associated with significantly higher and/or sustained levels of stress, which can contribute to pathophysiologica changes (Adler et al., 1994; Hogue & Bremner, 2005; McEwen, 1998; Seeman & McEwen, 1996). Conversely, access to and utilization of social support can have a beneficial effect on stress mediators (Seeman & McEwen, 1996). It appears that successful coping strategies (e.g., social support) can moderate stress responses so that recovery from a stressful event is enhanced, thereby preventing a potentially negative impact on the health of an individual (McEwen & Wingfield, 2003).

Perceptions of Psychological Stress and Health Outcomes in Pregnant Cohorts

There is a growing body of epidemiologic evidence to support the relationship between maternal psychosocial stress and adverse pregnancy outcomes. Although studies have varied in their approaches to investigating these phenomena, there are strong associations between maternal antenatal emotional states, chronic stress, and several perinatal morbidities including restricted fetal growth, low birth weight (LBW) and prematurity (Dole et al., 2003; Hoffman & Hatch, 2000; Rondo et al., 2003; Ruiz, Fullerton & Dudley, 2003; Stein, Lu & Gerber, 2000; Wadhwa, Sandman, Porto, Dunkel-Schetter & Garite, 1993). In addition, chronic stress due to intergenerational social and racial disparities has been proposed as a possible mechanism contributing to the higher rates of preterm births (PTB) and LBW infants born to African American women compared to other ethnic groups (Geronimus, 2001; Hogue & Bremner, 2005; Lu & Chen, 2004).
Anxiety and depression during childbearing have been associated with maternal obstetric complications such as prolonged labor and operative delivery (Chung, Lau, Yip, Chiu & Lee., 2001), as well as increased perceptions of vulnerability to illness for both women and their infants (Burger, Horwitz, Forsyth, Leventhal & Leaf, 1993; Poehlmann & Fiese, 2001). The presence of maternal psychological symptoms and perceptions of inadequate psychosocial support have been documented to contribute to poor pregnancy outcome (e.g., LBW) (Chung et al., 2001; Feldman, Dunkel-Schetter, Sandman & Wadhwa, 2000; Rich-Edwards & Grizzard, 2005; Rini, Dunkel-Schetter, Wadhwa & Sandman, 1999). Furthermore, maternal psychological symptoms can adversely affect maternal-infant relationships and children’s psychological development several months to years after birth (Kofman, 2002; Murray, Sinclair, Cooper, Ducournau & Turner, 1999; Susman, Schmeelk, Ponirakis & Gariepy, 2001; Van den Bergh, Mulder, Mennes & Glover, 2005).

Physiological Responses to Perceptions of Stress and Health Outcomes in Pregnant Cohorts

The physiological effects of maternal stress can have both short term and long-term effects on the fetus. Maternal physiological stress may cause adjustments in the development of the fetus that lead to growth restriction or a shorter gestational period (Pike, 2005). During pregnancy, maternal plasma CRH and glucocorticoid levels are elevated above normal pregnancy levels in several pathological conditions. Elevated CRH and glucocorticoid levels have been documented in women with pre-term labor and birth (Erickson et al., 2001), pre-eclampsia (Goland et al., 1995), restricted fetal growth (Goland et al., 1993), bacterial infections (Petralgia et al., 1995) and as a result
of perceptions of chronic psychosocial stress (Hobel, Dunkel-Schetter, Roesch, Castro & Arora, 1999). It has been suggested that perinatal complications such as PTB may be adaptive responses of the pregnant woman and her fetus to survive by “reducing stress on the pregnant woman and removing the fetus from an over-stressed environment” (Schulkin, 1999, p. 351).

Laboratory studies conducted in pregnant mammals have documented that noxious stress stimuli is associated with elevated cortisol levels in the fetus as well as the mother (Coplan et al., 1996; Takahashi, Turner & Kalin, 1998) resulting in increased fear responses in the offspring that persist into adulthood (Cratty, Ward, Johnson, Azzaro & Birkle, 1995). In humans, this type of “fetal programming” in response to maternal stress may ultimately result in adverse health consequences (e.g., type 2 diabetes mellitus, cardiovascular disease, hypertension, stroke) several decades after the index event that the fetus experienced in-utero (Barker, 2004; DiPietro, Costigan & Gurewitsch, 2003; Wadwha et al., 2002; Wadwha, 2005). Conversely, modifying factors, such as social support, may have a beneficial effect on responses to stress (McLean, Wingo, Hatfield-Timajchy & Floyd, 1993; Yen & Syme, 1999), by decreasing stress hormone levels with a consequent reduction in the risk of developing significant illness later in life (Taylor, Repetti & Seeman, 1997).

Childbearing women can have adverse health consequences that extend beyond the perinatal period. Maternal hypertension and diabetes during gestation may resolve during the postpartum period only to recur later in life (Moore, 2004; Roberts, 2004). Even women without a history of serious medical complications during pregnancy may experience physical sequelae postpartum as a result of giving birth and the demands of
infant care taking responsibilities. Symptoms such as fatigue (Kline, Martin & Deyo, 1998; Lee & Zaffke, 1999) and decreased functional ability (Kline et al., 1998; Otchet, Carey & Adam, 1999) are often experienced during the postpartum period, but may persist for extended periods of time in some women. The long-term effect of the persistence of such symptoms on the overall physical and psychological health of women is not known.

Theory of Allostasis

Allostasis is a dynamic systemic response to maintain physiologic stability when confronting changes or challenges (McEwen, 2000; McEwen & Wingfield, 2003). It is a theoretical framework for understanding how a person maintains regulation of body systems when confronting predictable and unpredictable events that may be stressful or perceived as being stressful. Allostasis provides a framework for understanding the complex responses to stressful events or conditions that can result in maintaining or improving health, or contribute to physiological and psychological deterioration (McEwen, 1998; Seeman & McEwen, 1996). Critical components included in the allostasis theory include a person’s genetic risk factors, early life events, lifestyle and health-related behaviors, and previous and current stressful social and environmental experiences (e.g., social hierarchies, personal or societal conflict, traumatic events, etc.) (McEwen, 2000; Schulkin, 2003).

Within the context of allostasis, stress is defined as “a physical or psychological challenge that interacts in a very significant way with lifestyles and rhythms” of the
individual (McEwen & Wingfield, 2003, p. 28). Homeostasis is the coordinated operation of physiological processes that maintain the steady state required to sustain life (e.g., regulation of the body’s pH, oxygen tension, glucose levels, thermoregulation). Allostasis is the mechanism by which the homeostatic systems are maintained in balance as an individual’s lifecycle and environment changes (McEwen & Wingfield, 2003) and involves the ongoing predicted regulation of stress mediators (e.g., ACTH, cortisol, CRH, NE and E) and body systems. Allostatic responses may result in alterations in the “set points” or boundaries of control in a person’s homeostatic systems in order to maintain this balance over time (McEwen & Wingfield, 2003).

There are different types of allostatic responses that can cause alterations or abnormalities at cellular or systemic levels (Figure 2.1). An allostatic state occurs when there is an elevated level of activity of allostatic mediators such as cortisol in response to a perception of stress. Normally the activity level of allostatic mediators returns to baseline once the perceived threat has resolved with little, if any, alteration in the individual’s set point for their homeostatic systems. However, when there is a chronic elevation or dysregulation of allostatic mediators, or both that is sustained over time, a condition known as allostatic load occurs. This condition can lead to changes in the target cells of allostatic mediators thereby altering an individual’s set point for homeostasis and resulting in pathophysiologic effects (e.g., increased blood pressure, abnormal high density lipoprotein cholesterol level). Allostatic overload occurs at the point when actual disease states or abnormal conditions (e.g., myocardial infarction)

Relevance of Theory of Allostasis to Childbearing Outcomes

The majority of pregnant women will proceed through pregnancy and the puerperium without developing serious complications. However, for some women the normal process of childbearing will be confounded by adverse events that may jeopardize their health and the health of their fetuses/newborns. In many instances, there are pre-existing medical conditions or other factors that may alert clinicians to a woman’s increased risk of having complications during childbearing, but for other women the reasons for experiencing adverse events during this time are unclear.

It is possible that abnormal allostatic responses to stress may partially explain the basis for the development of some adverse perinatal outcomes in women without identified medical risk factors. Monk, Myers, Sloan, Ellman & Fifer (2003) investigated maternal cardiovascular reactivity (as measured by maternal blood pressure and heart rate) and fetal heart rate (FHR) variability in pregnant women undergoing laboratory-induced stress (Stroop color-word matching test) during the third trimester. They found that 69% of the variance ($R^2 = .69, p < 0.001$) observed in FHR variability that continued for several minutes after the maternal standardized test had been completed was explained by maternal trait anxiety scores and maternal cardiovascular reactivity. This extended period of maternal and fetal cardiovascular reactivity may
reflect abnormal allostatic responses to the maternal stressful stimulus in anxious pregnant women.

Increased maternal anxiety (as measured by standardized state and trait anxiety scales) has been found to significantly increase uterine artery resistance (Teixeira, Fisk & Glover, 1999). The reduction in uterine blood flow associated with increased uterine artery resistance can reduce oxygen and nutrient transport to the fetus which if persistent could cause growth restriction and LBW. It is possible that the increase in uterine artery resistance observed in anxious pregnant women may represent a state of maternal allostatic overload. Similarly, responses to traumatic life events may contribute to suboptimal perinatal outcomes. Lederman and colleagues (2004) observed a significantly shorter length of gestation (-3.55 days; \( p = 0.001 \)) and smaller head circumference (-0.477 cm; \( p = 0.01 \)) in infants born to non-smoking pregnant women in New York who experienced their first trimester of pregnancy when the World Trade Center (WTC) disaster occurred. Although exposure to pollutants from the disaster is a possible factor contributing to these findings, the significant differences in the length of pregnancy and infant head circumference remained regardless of the distance the women lived or worked in relation to the WTC disaster. This suggests that psychological stress and responses to this stress during early gestation may alter perinatal outcomes. These findings may also reflect maternal allostatic overload in response to the psychological stress of experiencing a traumatic event.

Finally, maternal perceptions or experiences of chronic psychosocial stress during childbearing have been associated with adverse perinatal outcomes (e.g., PTB and LBW) (McCubbin et al., 1996), child psychological dysfunction (Gutteling et al.,
The role of allostatic load and overload in the development of these conditions has not been defined as yet, but it is possible that the exposure to and/or perceptions of chronic psychological stress results in a change in homeostatic boundaries that, while initially serves to promote survival of the individual, may also predispose an individual to the development of disease.

Clinical Implications

Currently, laboratory testing for allostatic mediators are primarily confined to research investigations and norms have not yet been established for what constitutes allostatic load. However, based on an emerging literature there is considerable promise for using the allostatic biomarkers to identify individuals at risk for the development of a variety of diseases (Table 2.2). For example, the March of Dimes has recently recommended six specific research priorities for investigating preterm births in the U.S. One of the areas identified is the “stress responses to preterm birth” (Green et al., 2005, p. 629). Both the biologic assessment of maternal and fetal stress and the effects of stress on racial/ethnic disparities are targeted areas for investigations into the links between stress and PTB. It is possible that the theory of allostasis will provide an important theoretical framework for developing research studies about PTB. In addition, allostasis could be used as the basis for developing and evaluating clinical interventions that might modify maternal perceptions and/or
experiences of stress and their impact on reducing other adverse childbearing and parenting outcomes.

From a clinical perspective, it is anticipated that future investigations into the role of allostatic states and health outcomes will assist in our better predicting complications associated with pregnancy (e.g., pre-eclampsia), diseases that often first appear in pregnancy (e.g., diabetes), and conditions that may first manifest during the postpartum period (e.g., depression) – especially in those women without identified risk factors for the development of these conditions. Similarly, there is a potential for identifying fetuses at high risk for intrauterine growth restriction or likely to be impacted in the newborn period or early infancy. It is also possible that an allostatic theoretical framework could be used to explore why only some perinatally-exposed infants develop congenital or postnatal infections (e.g., cytomegalovirus, herpes simplex virus, human immunodeficiency virus), and further identify psychological and physiological predictors of aberrant maternal infant relationships. Identifying a high likelihood of an adverse maternal or infant outcome would be important in order to mobilize appropriate therapeutic interventions early in gestation to interrupt or minimize a disease process.

Strategies that can be employed to modify potentially harmful stress responses in childbearing women include the identification of maternal psychosocial conditions (e.g., anxiety, depression, substance use, history of trauma/violence) that are associated with increased perinatal complications, and the implementation of interventions that have been documented to assist with stress reduction. For example, significant decreases in adverse consequences of maternal stress have been
associated with the use of relaxation techniques (Teixeira, Martin, Prendiville & Glover, 2005), yoga (Narendran, Nagarathna, Gunasheela & Nagendra, 2005), acupuncture, reflexology, and therapeutic touch (Tiran & Chummun, 2004).

Assisting childbearing women in accessing available health care and community resources to support optimal maternal and infant outcomes (e.g., Women’s, Infants’ and Children’s nutritional supplements, substance abuse programs) is essential. Finally, providing childbearing women information about how to identify and reduce stress in their lives can afford them the opportunity to actively engage in their own health promotion. These interventions can be implemented now while research is being developed that can further clarify how allostatic states may, in fact, impact maternal-fetal-neonatal health outcomes.

Conclusion

The conceptual basis for understanding the effects of perceived stress, coping, and adaptation in childbearing women is complex. The multifactorial nature of these phenomena requires an appreciation of the interrelationship of the contextual elements of the lives of women that includes psychosocial, cultural, physiological, and environmental components. Antecedent events influence the strategies that women use to cope with predictable and unpredictable challenges that occur as the maternal-infant relationship evolves. In order to be able to investigate these phenomena, a theoretical framework that includes the multiple dimensions and possible short-term and long-term health outcomes of women and their infants is essential. The theory of allostasis
provides a framework for conducting research to explore and more fully grasp the intricate elements of stress, coping, and adaptation in childbearing women and their fetuses/infants during critical points in their lives. In addition, this theory may also provide an opportunity to evaluate clinical interventions that may benefit childbearing women and their families.
Chapter 3.

HIV-Infected Mothers’ Foci of Concern During the HIV Viral Testing of Their Infants
Background and Significance

The majority of women with human immunodeficiency virus (HIV) infection in the United States (U.S.) are in their childbearing years (Centers for Disease Control and Prevention [CDC], 2006a). HIV-infected women who become pregnant have the option to receive highly active antiretroviral therapy (HAART) both to reduce perinatal HIV transmission as well as to delay maternal disease progression. It has been documented that the use of HAART significantly reduces the risk of perinatal transmission from 25% to less than 2% (Perinatal HIV Guidelines Working Group of the U. S. Public Health Service Task Force, 2006). As a result, the vast majority of HIV-infected pregnant women in the U.S. are expected to give birth to uninfected, healthy infants. However, successfully integrating and coping with this new parental role in the face of this complex chronic disease is recognized as a significant daily challenge (Hackl, Somlai, Kelly, & Kalichman, 1997; Murphy, Koranyi, Crim, & Whited, 1999; Nelms, 2005).

A major concern for most childbearing women is whether or not they will be able to cope with parenting responsibilities and be a competent mother (Mercer 2004; Mercer & Ferketich, 1995). In HIV-infected pregnant and postpartum women this concern is compounded by a number of other issues including a protracted period of uncertainty about the health of their infants, the administration of prophylactic medications to reduce the likelihood of HIV infection of their infants, and maternal health issues (e.g., monitoring HIV symptoms and adherence to HIV medications, attendance at medical appointments). Unlike testing that is used to diagnose other serious chronic diseases prenatally and in infancy (e.g., chromosomal abnormalities,
sickle cell disease, cystic fibrosis), a definite diagnosis about a perinatally-exposed infant’s infection status is not available to mothers until repeated tests are done over a period of several months. It is possible that the complex process of infant HIV testing, albeit necessary to diagnose HIV infection, may contribute to increased maternal perceptions of anxiety, depression, and guilt (De Matteo, Wells, Goldie & King, 2002; Faithfull, 1997), which might result in a decline in immune function (Ikovics et al., 2001) and increased risk of HIV-related morbidities in infected mothers (Ickovics et al., 2001; Ickovics et al., 2006). In addition, maternal psychological symptoms during this time may contribute to the development of an aberrant maternal-infant relationship that can have long-term sequelae for the infant (Essex et al., 2006; Moses-Kolko & Roth, 2004; Moehler, Brunner, Wiebel, Reck, & Resch, 2006).

Even though the majority of infants born to HIV-infected women in the U.S. will not have the disease, the HIV status of these infants is not immediately known. In order to diagnose infection as soon as possible in perinatally exposed infants, an initial HIV viral test is usually performed within 48 hours after birth (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006). Approximately 20 – 30% of HIV-infected infants have had early in-utero transmission and will, therefore, have a positive result from their initial viral test (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006). However, if the initial test result is negative, a second HIV viral test is usually performed between 2 and 4 weeks of age and, if this result is also negative, a final viral test is performed between 16 and 24 weeks of age (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006). Through this
testing process, 99% of infected infants are diagnosed during the first four months of life (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006). Therefore, negative HIV viral test results during this period of time can be reassuring to parents. However, there is emerging evidence that chronic, intermittent maternal perceptions of uncertainty about an infant’s HIV infection status during the period of diagnostic testing has the potential to contribute to maternal psychological and physiological distress (De Matteo et al., 2002; Faithfull, 1997; Nelms, 2005; Santacroce, 2000). The consequences of this distress on maternal health, health behaviors, and the maternal-infant relationship have not been well studied. Currently, there is no scientific literature that has prospectively investigated HIV-infected mothers’ perceptions and concerns during the period of time that their perinatally-exposed infants are undergoing HIV viral testing. The purpose of this study was to explore and describe HIV-infected mothers’ primary concerns during the period of HIV viral testing of their infants in order to add to our knowledge about this process and to assist clinicians in their provision of care during this critical period of transitioning to parenthood.

Methods

Study Design

This study was part of a prospective, longitudinal, repeated measures investigation of HIV-infected pregnant and postpartum women and their infants conducted from September 2004 through January 2007. Participants had a total of six visits, one during the third trimester of pregnancy (T0), and five (T1A – T3) subsequent
visits after delivery. During the months that an infant was undergoing HIV viral testing, data were collected the week prior to the scheduled date of the infant’s HIV viral test and subsequent to the mother’s receipt of the infant’s HIV test results. Data collection time points were timed to capture information about maternal perceptions and concerns associated with the infant’s second HIV viral test ($T_{1A}$) and its result ($T_{1B}$), and the infant’s 16 to 24 week HIV viral test ($T_{2A}$) and its result ($T_{2B}$). A final study visit ($T_3$) was conducted at least four weeks after the final HIV viral test result was received by the mothers. The final study visit occurred at a time other than when infant medical appointments for routine pediatric (e.g., immunizations) or acute care visits had occurred. One investigator conducted all study visits, with the majority of visits taking place in mothers’ homes or another private location selected by them.

During each study visit, women completed standardized instruments to measure stress and psychological symptoms, and a questionnaire that collected demographic, health-related, and medication adherence information about the mothers and their infants. At each study visit mothers were also asked three questions about issues that might be of concern for them at that point in time. Mothers were to select from a list of items presented in Table 3.1 and/or write down other items that were of most concern for them. Items included as options in the list were developed based on reports in the literature that addressed motherhood within the context of HIV disease, and the clinical experience of the investigators. In response to the first question, participants could select as many items as they felt applied to their situation at the time of the study visit. Once they had completed their responses for the first question, they were asked to choose the one item from their previous selections that was the most worrisome for
them, and provide an explanation about their choice. In addition, mothers were asked to respond to the following question, “If you had one word to describe how you feel about the HIV testing process of your baby what would it be?” During the last study visit mothers were asked five open-ended questions about the HIV testing process of their infants and their participation in the study. Maternal responses were audiotaped and transcribed for analyses. Participants received a $25 grocery voucher as compensation for their time after the completion of each study visit.

Participant Recruitment and Sample

The study was approved by the Institutional Review Board (IRB) of the University of California, San Francisco and the Alta Bates-Summit Medical Center. Eligibility criteria for enrollment included: HIV infection; at least 18 years of age; able to read and write English; in the third trimester of pregnancy with a viable fetus; planning to live with and care for the infant after birth; and willingness to complete all study visits. HIV-infected pregnant women meeting eligibility requirements were informed about the study during the third trimester of pregnancy by the investigators at recruitment centers, through IRB approved flyers, or through an IRB-approved letter sent to clinicians providing health care to HIV-infected pregnant women. Women interested in participating in the study contacted one of the investigators using a confidential telephone number. During the initial contact, eligibility criteria were reviewed and women’s questions about the study were answered. Written informed consent was obtained from women during visit with one of the investigators.

The purposive sample consisted of twenty-one HIV-infected, English-speaking women who were in the third trimester of their pregnancy at enrollment. One of the
women was withdrawn from the study after the second study visit because it was determined that her HIV infection was caused by a viral clade (i.e., strain) that is not detected by HIV-1 DNA polymerase chain reaction (PCR) assays currently available for clinical use. Therefore, the infant was to undergo HIV antibody testing between 12 and 18 months to determine the presence or absence of infection. In addition, two women were lost to follow up for their final study visit. The remaining women completed all six study visits.

Data Analysis

The analyses for this paper addressed maternal issues identified by women as most concerning and their single word responses about infant HIV testing over time. Participant responses to specific questions were analyzed using content analysis. Content analysis involves the systematic coding, categorization, and analysis of verbal or written text to better appreciate the content of the message being conveyed (Denzin & Lincoln, 2000; Gilliss & Jackson, 2002). Categories are identified from the data as they are collected or can be established a priori based on theoretical concepts and/or evidence from published literature (Burns & Grove, 2001). Definitions and/or rules are developed to ensure that the investigator(s) code and categorize items in the same way (Gilliss & Jackson, 2002; Gottschalk & Bechtel, 1995). As a result of these processes, themes are identified about the phenomenon that is being investigated.

Women’s responses to the questions about their issues of concern were reviewed and classified into one of three categories: fetus/baby health focused, maternal health focused, and other non-health (e.g., psychosocial, economic) focused. These categories were defined a priori based on reviews of the literature about the experience of
motherhood within the context of HIV (Ingram & Hutchinson, 1999; Sandelowski & Barroso, 2003). The data collection instrument is presented in Table 3.1. Women’s written explanations about why they had chosen a particular item as the most worrisome at that point in time were also analyzed. The analysis of the women’s responses and explanations were initially completed by one investigator and then reviewed by two other experts in content analysis.

Maternal single word responses about the process of infant testing for each visit were analyzed and categorized by their emotional valence. Emotional valence is the affective tone or characteristic that can be associated with an event, object or language (Bestgen, 1994). Positive valences are assigned to pleasant or positive stimuli, negative valences to unpleasant stimuli, and neutral valences to neutral stimuli. Items with positive and negative stimuli have been documented to consistently stimulate different areas of the brain (Paradiso et al., 1999). This technique was used to rate emotional valence of the words used by the women as they described their perceptions about the HIV testing process of their infants for each time point in the study.

Investigators independently reviewed women’s single word responses for each visit and placed each response into one of three categories of emotional valence: 1) positive (the word reflected a positive perception/feeling about the infant’s HIV testing process); 2) negative (the word reflected a negative perception/feeling about the infant’s HIV testing process); and 3) neutral (the word did not clearly reflect either a positive or negative perception/feeling about the infant’s HIV testing process). Some women offered an explanation about their reasons for selecting a particular word. These were written down and the investigators included these in their classification of the emotional
valence. In the few instances (14%) where there was disagreement among reviewers about the assignment of emotional valence, discussions took place until consensus was reached.

Results

Sample Characteristics

Demographic characteristics and clinical features of the twenty study women are presented in Table 3.2. The average length of time that women had known about their HIV infection was 8.7 years (range = 4 months – 24 years); two participants were diagnosed with HIV infection during the current pregnancy. All of the participants received combination antiretroviral (ARV) medications during their pregnancies, with 75% planning to continue after childbirth for treatment of their disease.

The women had a total of 44 living children with three reporting that some of their children were living in other households during the study period. Women with living children reported that all of the children previously born to them were HIV negative. One woman had experienced the death of an infant as a result of HIV infection two years prior to the current pregnancy. All of the infants born to the participants during this study received prophylactic ARV medications for six weeks after birth, and all were determined to be HIV negative by viral testing.

Foci of Maternal Concern

Figure 3.1 presents the percentage of women who identified each concern at least once over the course of the study. At some point in time every woman expressed concern about her infant’s health as well as her own health. During the antepartum
period, maternal concern about having a safe birth was more frequently identified then other pregnancy-related issues. A majority of the women were worried about disclosure of their infants’ HIV testing and/or medications (80%) or their own HIV infection (60%) to persons they did not want to know about these situations. Women were also concerned about HIV medications. However, a larger percentage of women were concerned about their infants’ medications (60%) than about their own regimens (40%). Finally, more women identified financial concerns during the study period than any of the other psychosocial issues.

Figure 3.2 presents women’s identified issues of greatest concern during the study time points. HIV-infected mothers’ foci of greatest concern changed over time, with a temporal association evident between different maternal foci of concern and infants’ HIV viral testing points. During the third trimester of pregnancy, 80% of the women identified a fetal/infant health issue as the “issue of most concern” for them, with the majority of these women selecting transmission of HIV infection to the fetus/infant as being the most worrisome concern. Women provided various reasons for this concern.

I’m worried that if the baby is infected it would be difficult for her to live.

Because of my experiences I know how hard it is – mainly the way kids treated me, but some of the medical things, too. (Mother #16 who was perinatally infected)

I was infected by someone else, so I know what it’s like and I don’t want to infect anyone – especially not my baby. All I want is this child to be well
and for me to have made a good decision about having a baby. (Mother #11)

Only one woman identified concern about fetal/infant ARV medications as the most worrisome issue.

The drugs are very strong. AZT stops [HIV] DNA from reproducing and it seems a very harsh step for a newborn to endure. We don’t know enough about long-term effects but to be treated so differently during pregnancy [with HIV medications] when other mom’s don’t even take an aspirin. (Mother #12)

Of the remaining women, two cited a maternal health focus as being the most worrisome at this point (“having a safe birth without problems”), and two others selected issues not related to either fetus/infant or maternal health (“having enough money to live” and “your spouse/partner leaving you”). None of the women identified their HIV infection or their HIV medications as being the most worrisome concern for them at this point in their pregnancies.

After childbirth, infant health issues continued to be the primary focus of the women’s concern during the period of time just prior to their infants’ undergoing the second (T1\textsubscript{A}) and the final (T2\textsubscript{A}) HIV viral tests (e.g., 80% and 55%, respectively). A shift in maternal foci of concern was observed after the women received each negative test result for their infants. After the women received the result from the second viral test (T1\textsubscript{B}) their focus on infant health issues dropped from 80% to 40%. However, there was a rebound of maternal concern about infant health issues up to 55% just prior to the infant’s next HIV viral test (T2\textsubscript{A}). This rebound was followed by a precipitous decline in maternal focus on infant health to 20% after the final viral test result was received by
the women (T2_B). At the time of the final study visit (T3), only 5.5% of the women cited an infant health issue as being of greatest concern, and none of them identified HIV transmission to the infant as being an issue of concern. Infant ARV medications were not cited as a major concern after the women gave birth.

Throughout the infants’ HIV viral testing processes, few women identified maternal health issues (e.g., HIV infection, HIV medications) as being their most worrisome concern. Women who did identify maternal health issues as being most worrisome to them often reflected on the effect of infant care taking responsibilities on their own health and health behaviors.

I missed four days of meds in a row - last week – over the weekend – about a week ago. It was a combination of forgetting and not being able to deal with it, the meds. I don’t understand why I did that. This being a mom is a whole other level of responsibility and if something has to go it usually is the mommy’s thing [e.g., meds]. (Mother #6 during the study visit after her infant’s second negative test result had been received)

I just want to know how bad it [HIV infection] is since I’ve been off my meds. I want to know if I need to start the meds and if I can start again if I have to. It would be easier now (to take meds) because my daughter isn’t on anything [meds] anymore. (Mother #1 during the study visit after her infant’s final negative viral test result had been received)

Women’s concern about their own health did not surpass infant health as their most worrisome concern until the results from the infants’ final HIV viral tests were
known (T2b). Although more women selected maternal health-related issues during the final study visit, only a third perceived their own health as the most important issue of concern. In addition, they often placed concern about their health within the context of the need for them to survive so they could take care of their infants.

I don’t know my latest test results and my CD4 count is dropping. And I’m concerned about being around for him now. (Mother #11 during the final study visit)

My HIV infection is a concern because it’s impacting my entire life – my ability to work and be there for my daughter. Guardianship at age 44 wouldn’t be an issue if I didn’t have this disease. (Mother #8 at the final study visit)

Women identified other issues that were not related to infant or maternal health but reflected several psychosocial and economic challenges they confronted at various time points in the study. These other issues did not surpass their concerns about infant health until the results of the final infant viral test result had been received. The most frequently reported concern in this category was “having enough money to live.” Other issues cited included HIV disclosure to persons that the women did not want to know about their infection status or their infants’ HIV testing/medications, guardianship for their infants, personal problems with relatives or friends, abandonment by their partners, or having their children taken away from them. Some of these issues (e.g., inadvertent disclosure about HIV issues) seemed to reflect the mother’s worry about the possibility
of experiencing a negative social consequence due to the presence of HIV infection in their and their infants’ lives.

I just don’t want anybody to know about it – the testing, the medicines. Just don’t want anybody to find out. (Mother #5’s statement about why disclosure of her infant’s HIV testing and medications was a major concern for her.)

This whole HIV thing was my mistake, my fault. I don’t want her to take the blame for it. It wasn’t her fault. She didn’t ask to be in this situation and I don’t want them using it against her. (Mother #10’s statement about why disclosure of her infant’s HIV testing and medications was a major concern for her.)

*Emotional Valence*

Figure 3.3 presents the results of the emotional valence categorization of the women’s responses by the investigators. Women used more words with a negative emotional valence prior to infant testing (e.g., “overwhelming”, “scary”, “invasive”). Words with a positive emotional valence (e.g., “good”, “relieved”, “happy”) increased in frequency after each negative test result for their infants became known. Although all of the infants in this study had negative viral test results indicating that they were uninfected, almost a third of participants continued to use words with a negative emotional valence to describe the testing process at the final study visit (T3) conducted several weeks to months after infant viral testing had been completed.
Discussion

This is the first prospective, longitudinal study to explore HIV-infected mothers’ foci of concern during the HIV viral testing of their infants. The results of the study indicate maternal concerns changed over time and demonstrated a temporal pattern in association with planned infant viral testing time points and maternal receipt of infant test results. Similar to other reports about HIV-infected mothers’ experiences (Hackl, et al., 1997; Ingram & Hutchinson, 1999; Sandelowski & Barrosa, 2003), participants in this study identified HIV transmission to their fetus/newborn as a major worry. Mother to child transmission of HIV was especially worrisome during pregnancy and the first few weeks postpartum. This adds to prior evidence documenting that HIV uninfected childbearing women express concerns about having a healthy baby during the prenatal period (Statham, Green & Kafetsios, 1997; Viau, Padula & Eddy, 2002), and focus most of their attention toward maintaining the health and survival of their infants after birth (Sword & Watt, 2005). While HIV-infected mothers may experience worries about a healthy outcome for their infants that are similar to uninfected mothers, these mothers must confront the additional burden of the risk of transmitting HIV infection to their infants during pregnancy and birth, as well as the uncertainty about the infection status of their infant for several weeks to months after delivery.

Maternal concerns about fetus/infant health continued to dominate their thoughts while their infants were undergoing HIV viral testing and receiving medical interventions to prevent HIV infection (e.g., administration of prophylactic ARV and
PCP medications). However, once the women received results from their infants’ final viral test at $\geq 16$ weeks of age, and medical interventions targeting the prevention of HIV infection were no longer needed, there was a dramatic decline in infant health as the primary focus of their concerns. At this point in time, there was a shift in maternal concern to “other” (non-health related) issues that are necessary to maintain family psychosocial stability. Paramount among these was the financial insecurity faced by a number of the mothers. Although the average monthly household income prior to taxes in this cohort was above the poverty level, a large percentage of the women acknowledged that their current income was inadequate to support their families’ living expenses. In situations where finances are limited and there is a need to determine priorities for expenditures, HIV-infected mothers may have to decide about whether or not they can afford to invest in some medical interventions that are essential to their health (e.g., payment or co-payment fees for HIV medications) when they are having difficulty paying for the basic necessities for their children/family.

In addition to concern about financial security for themselves and their families, many of the women identified inadvertent HIV disclosure as a major worry. Women’s primary concern was the potential for negative social consequences (e.g., loss of partner or family support) that might occur should their HIV infection status become known. Interestingly, although some women acknowledged that they had already disclosed their HIV infection status to relatives and/or friends prior to their pregnancies, some of these same mothers worried that disclosure about their infants’ HIV testing and need for ARV medications to some people in their communities might result in punitive actions against their infants when they were older (i.e., entering school). This finding is
consistent with those of Sandelowski and Barroso (2003) who identified two major
goals in their metasynthesis of studies investigating motherhood in HIV-infected
mothers, specifically to protect their children from HIV infection and to protect their
children from HIV-related stigma.

This study also demonstrated an overall lack of women’s concern about
maternal health issues until after they knew the results of their infants’ final viral test.
Even when there was a shift in maternal focus away from fetal/infant health issues,
maternal health issues never surpassed economic and psychosocial issues as a major
focus of concern. A lack of focus on maternal health is not unusual for women during
the first few weeks postpartum when infant care taking demands are high (Mercer,
2004). However, a sustained lack of concern by HIV-infected mothers about their own
health could lead to a delay in medical evaluations and interventions that are needed to
improve and/or maintain maternal physical and emotional well-being. In our cohort,
mothers’ recognition of the importance of maintaining their health was often described
as necessary for the health and survival of their infants. Other studies have documented
that while HIV-infected mothers are motivated to take better care of their health so they
can survive and raise their children, they frequently place their children’s needs ahead
of their own (Bunting & Seaton, 1999; D’Auria, Christian & Miles, 2006). Butz and
colleagues (1993) found that in their cohort of 99 HIV-infected mothers and their
infants, 72.9% of the infants received recommended immunizations by nine months of
age while only 45.6% of the mothers ever received any health care during the same
period of time. In general, medical evaluations for HIV-infected individuals with
asymptomatic, stable disease usually occur every 3 to 4 months (Panel on Antiretroviral
Guidelines for Adults and Adolescents, 2006). For HIV-infected women receiving complex ARV regimens or those with advanced disease and/or co-existing conditions (e.g., hepatitis), inconsistent medication adherence or a delay in medical evaluations for several months increases the risk of maternal morbidity.

A third of the women in this study maintained a negative perception about their infants’ HIV testing at the final visit, even though viral testing was no longer needed and their infants were considered to be uninfected at this point. This perspective may reflect maternal concern about the need for their infants to undergo the HIV antibody testing that is currently recommended at 12 to 18 months of age for all perinatally infected infants who have had negative viral tests (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006). Although antibody testing at this time is intended to document the loss of maternal IgG antibodies that an HIV-exposed infant acquires in-utero, mothers may be experiencing anxiety about their infants having to undergo yet another laboratory test for HIV. For many of the women, the physical act of obtaining a laboratory specimen from their infant was upsetting and frustrating for them to witness.

It is difficult to watch the phlebotomist search for her veins – to try & try again while she is screaming her head off – It is trying.

(Mother #12 explaining why she had chosen the word “trying” to describe the HIV testing process of her infant during the final study visit.)

. . . but at this point it is just painful to have to wait 12 more months to have the final test done [the antibody test], and not have to have any more tests. It’s
a lingering question mark until that test is done, so I’m feeling in limbo a bit.

(Mother # 11 explaining why she had chosen the phrase “drawn-out” to
describe the HIV testing process of her infant during the final study visit.)

Studies have documented that even after an exposed infant has completed all HIV
testing and is found to be uninfected, some mothers continue to worry that their children
may be infected because the diagnosis might have been missed by clinicians or that the
previously done HIV tests were unreliable (DeMatteo et al., 2002; Faithfull, 1997).
How this protracted worry and uncertainty about an infant’s HIV infection status
impacts HIV-infected mothers’ perceptions of the overall health of their infants in the
long-term is not known. In addition, the effects of infected mothers perceptions of
uncertainty about their infants’ health on the maternal-infant relationship remains to be
elucidated. Studies have documented aberrant maternal-child interactions in uninfected
mothers who perceive their healthy infants to be medically vulnerable because of brief
hospitalizations of the infants for the treatment of physiological jaundice (Kemper,
Forsyth & McCarthy, 1989; Kemper, Forsyth & McCarthy, 1990) or
misunderstandings about “benign” conditions such as functional heart murmurs
(Bergman & Stamm, 1967; Pearson & Boyce, 2004). It is possible that a lack of clarity
about an HIV-exposed infant’s health status may result in a type of “tentative”
attachment on the part of infected mothers, a situation where they may have some
emotional distancing from their infants as a means of coping with the possibility that
their infant’s negative test results are incorrect.
Limitations

While the mothers in this cohort represent a diverse group of HIV-infected women, there are several limitations to this study. The small sample size and the demographic and HIV characteristics of the mothers limit extrapolation of findings to other populations of HIV-infected women. HIV-infected women who are more symptomatic of HIV disease might have different foci of concern. They may focus more on maternal health issues and be less worried about other non-health issues during this period of time. All of the women enrolled in this study were engaged in specialized pregnancy and HIV care, and their infants were involved in specialized HIV pediatric clinical services. Women without access to specialized perinatal and pediatric HIV clinical services might have more negative perceptions about the testing process because of the limited educational, medical, and social resources available to them during this stressful period. The majority of women in the study had knowledge of their HIV infection that pre-dated their pregnancies. Women newly diagnosed with HIV during pregnancy may have different perceptions of concern (i.e., maternal health concerns equal to or surpassing infant health concerns during pregnancy) because of the time that might be required to integrate the diagnosis of HIV into their lives. However, in this study the two women who were newly diagnosed during pregnancy reported that their focus of concern prenatally was the health of their fetus and neither prioritized their own health over their infants at any time point. None of the women had a history of injection drug use, and none had personally reported illicit drug use during the pregnancy. However, one woman who had a history of drug use prior to her pregnancy did experience a relapse after receiving her infant’s final viral test result, and was lost to
follow-up at the final data point for the study. It is unclear what HIV-infected pregnant and postpartum women who are actively using drugs might identify as their most worrisome issues. In addition, some mothers with active drug use problems are often separated from their infants for several weeks, months or years. Depending on the circumstances of the separation, some of these mothers may have different patterns of concern from the women in this study.

Clinical Implications

The clinical care of HIV-infected mothers and their affected families is complex and, ideally, involves an interdisciplinary team approach that includes clinicians (e.g., adult and pediatric HIV specialists), social workers, therapists, and other community agencies to assist with multiple challenges they face on a daily basis. Results of this study suggest that there may be specific time intervals where HIV-infected mothers are particularly vulnerable and might benefit from targeted interventions for any psychological distress they might be experiencing in relation to their infants’ HIV viral testing. The majority of mothers in this study demonstrated that their primary focus was on health issues of their infants and, until the infants’ completed their viral testing and received an “uninfected” clinical diagnosis, neither maternal health nor other non-health related issues were considered a priority. However, delays in addressing maternal health, as well as socioeconomic and psychological issues of the family, can place the mother and her family at risk for adverse consequences (e.g., increased risk of illness in the mother, loss of secure housing, abandonment by partner or others).
Awareness on the part of health care providers about HIV-infected mothers’ focus on their infants, and the lack of focus on maternal health, can guide them in their assessment of the mothers’ needs during this critical period so that specific interventions can be implemented. For example, HIV specialists who provide clinical care to pregnant infected women could arrange for a medical appointment or telephone call during the first few weeks postpartum with those women who are planning to continue to take their ARV’s to assess how well they are adhering to their medication regimen. Pediatric clinicians conducting examinations of the infants can specifically ask mothers about their health: how they are feeling, when medical appointments are scheduled for them, and how well the mothers are able to take their medications. Such queries might elucidate important problems such as delays in maternal access to health care, symptoms of psychological distress or HIV disease progression, and/or difficulties with adherence to medications. In addition, these queries may lead to early interventions that serve to maintain or improve maternal health while demonstrating clinicians’ appreciation and support of the importance of HIV-infected mothers involvement in the care of their infants. Furthermore, other issues such as maternal concerns about financial constraints and HIV disclosure should be addressed when providing comprehensive care to this group of mothers and their infants.

Conclusion

Concerns about fetal and infant health are foremost for HIV-infected women becoming mothers until after their infants’ final HIV viral test result is known. In the majority of infected mothers, concerns about maternal health, specifically their HIV
infection and antiretroviral medications, does not surpass that of infant health concerns until several months postpartum. Maternal focus on infant health issues, as well as other psychosocial difficulties, may interfere with infected mothers accessing clinical services that are necessary for maintaining their health; however, interventions to assist HIV-infected mothers during this period of time may improve maternal health outcomes as well as support a healthy maternal-infant relationship.
Chapter 4.

Perceptions of Uncertainty, Stress, Distress and Social Support in HIV-Infected Mothers During the HIV Viral Testing of Their Infants
Introduction

In the United States (U.S.), an estimated 7,000 – 8,000 HIV-infected women give birth each year (Centers for Disease Control and Prevention [CDC], 2006b). The number of perinatally HIV-infected infants declined from a peak incidence of 1650 per year in 1991 to less than 250 per year in 2002 (CDC, 2006b). This dramatic decline in perinatal infection is primarily attributed to the identification of HIV-infected pregnant women and the subsequent implementation of prophylactic interventions that interrupt viral transmission from an infected mother to her fetus (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2006).

Although a negative infection status is the anticipated outcome for the vast majority of perinatally-exposed infants in the U.S., the process required to confirm whether or not an infant is infected involves a number of HIV viral tests over several months.

Similar to the general population of childbearing women, HIV-infected women who are transitioning to a maternal role face the usual stresses of new motherhood. However, during the critical period of their infants’ HIV testing, they must cope with additional stressors that include their own health care, the unknown infection status of their infants, and attending to their infants' unique needs such as the administration of prophylactic medications to interrupt HIV infection and prevent *Pneumocystis jerovecii* pneumonia (PCP). In addition, these women face uncertainty about the morbidity and mortality associated with their own disease, how long they will actually be able to take care of their children, social stigma, and the unknown long-term effects of infant exposure to antiretroviral (ARV) medications (Bennetts et al., 1999; Murphy, Koranyi, Crim, & Whited, 1999; Nelms, 2005). Maternal psychological distress about an infant's
HIV infection status may also have a long-term impact on the maternal-infant relationship (Essex et al., 2006; Moehler, Brunner, Wiebel, Reck & Resch, 2006). There is limited information that addresses the HIV-infected mother’s experiences with infant diagnostic testing for HIV infection. Some studies report increased maternal uncertainty about both the mother’s and infant’s health and increased maternal psychological symptoms (Faithful, 1997; Hackl, Somlai., Kelly & Kalichman, 1997; Santacroce, 2000; Sharts-Hopko, Regan-Kubinski, Lincoln & Heverly, 1996). Although these studies help elucidate some of the challenges faced by mothers during infant testing, there are several limitations. The majority of studies employed a cross-sectional design at various time points in the testing phase of the infants. Infants’ ages ranged from 3 to 18 months and the final HIV status for the majority was still uncertain at the time of data collection. Most of the data were collected prior to 1999 when interventions to reduce mother-to-child-transmission of HIV involved monotherapy or two-drug therapy instead of highly active antiretroviral therapy (HAART), a more potent approach using at least three ARV drugs to suppress maternal viral load. As a result, the reduction of maternal transmission to the infant during the time of these studies was approximately 5 – 10% compared to less than 1% that has been documented since HAART regimens began (Perinatal HIV Guidelines Working Group of the U.S. Public Health Service Task Force, 2006). Finally, most infants in these studies underwent HIV antibody testing, rather than HIV viral testing, which resulted in a prolonged testing period and a delay in a final HIV diagnosis for the infants until 18 months after birth.
There are no studies in the literature that have specifically addressed maternal experiences prospectively during the HIV viral testing process of perinatally-exposed infants. This process differs from HIV antibody testing of infants, in that it usually involves three to four viral tests that span from birth to 4 or 6 months of age with at least 99% of infected infants diagnosed by 4 months of age. Therefore, the purpose of this study was to describe HIV-infected mothers’ perceptions of uncertainty about infant health, stress, distress, and social support during the HIV viral testing process of their perinatally-exposed infants.

Methods

Human Subjects Approval and Subject Recruitment

Institutional Review Board (IRB) approval for the study was obtained from the University of California, San Francisco and the Alta Bates-Summit Medical Center. Eligible women from Northern California included those who: 1) were 18 years of age or older; 2) were HIV infected; 3) anticipated the birth of a viable infant without life threatening conditions or congenital anomalies; 4) would be living with and caring for their infant after delivery; 5) spoke and read English; and 6) were willing to participate for the duration of the study.

During the third trimester of pregnancy, eligible HIV-infected pregnant women were informed about the study by the investigators at recruitment centers, through IRB approved flyers describing the study posted at these centers, or through an IRB-approved letter outlining the study that was sent to clinicians who were known health care providers for HIV-infected pregnant women. Interested women contacted the first
author using a confidential telephone line. During the initial discussion, eligibility criteria were reviewed and women’s questions about the study were answered. Written informed consent was obtained from women during a face-to-face visit with the investigator. All research documents were stored in a locked filing cabinet that was accessible only to the first author.

**Study Design**

This prospective, longitudinal, repeated measures study of HIV-infected pregnant and postpartum women and their infants was conducted from Sept 2004 through January 2007. Participants had a total of six visits; one during the third trimester of pregnancy (T0), and five subsequent visits after delivery. After delivery, HIV-infected mothers completed a study visit during the week prior to the scheduled date of the infant’s HIV viral test and then subsequent to the mother’s receipt of the infant’s HIV test results. Visits for the study were timed to capture data about maternal perceptions and concerns associated with the infant’s second HIV viral test (T1\textsubscript{A}) and its result (T1\textsubscript{B}), and the infant’s 16 to 24 week HIV viral test (T2\textsubscript{A}) and its result (T2\textsubscript{B}). A study visit for the first infant HIV viral test was not done because this is typically completed within 48 hours after birth and events surrounding the intrapartum and neonatal periods could substantially confound the data being collected. The final study visit (T3) was conducted at least four weeks after the final HIV viral test result was received by the mothers, and occurred at a time other than when infant medical appointments for routine pediatric care (e.g., immunizations) were planned or acute visits had occurred. The majority of study visits were conducted in the mother’s home or another location of her choice that provided privacy.
Data were collected using standardized questionnaires to determine self-report levels of uncertainty, stress, distress, and social support and are further described below. Demographic information, maternal and infant health status, and responses to open-ended questions developed by the investigators addressing the mother’s experience about their infant’s testing were also obtained.

**Instruments.**

*Perceived Stress Scale-10 Item (PSS-10).* The PSS-10 is a self-administered scale that was developed to measure “the degree to which situations in one’s life are appraised as stressful” during the past month (Cohen, Kamarck & Mermelstein, 1983, p. 386; Cohen & Williamson, 1988, p. 33). It uses a Likert-type 5-point response format that ranges from 0 ("never") to 4 ("very often"). Four of the 10 items are scored in reverse direction and added to the sum of the scores calculated for the other six items. The range for scores is 0 to 40 with higher scores on the PSS-10 reflecting greater perceptions of stress. The PSS-10 item has adequate internal reliability (alpha coefficient = .78) (Cohen & Williamson, 1988). The Cronbach alpha coefficient for this sample was .90.

*Center for Epidemiological Studies-Depression (CES-D) Scale.* The CES-D scale is a self-administered depression screening tool developed to estimate the frequency of depressive symptoms in the general population (McDowell & Newell, 1996). It consists of 20 items that reflect two dimensions of perceived well-being: positive affect and depressive affect. Four items are positively worded to reduce response bias as well as to demonstrate positive perceptions about a person's sense of well-being (McDowell & Newell, 1996). It uses a Likert-type 4-point response format
that ranges from 0 ("rarely or none of the time, less than 1 day") to 3 ("most or all of the

time, 5-7 days"). Once the scores for the four positive items are reversed, the sum of
the 20 items is calculated and can range from 0 to 60. A score of 16 or higher indicates
significant depressive symptoms (McDowell & Newell, 1996; Radloff, 1977).

Cronbach alpha coefficients range from 0.85 for samples from the general population to
The CES-D has been used in several studies investigating depressive symptoms in HIV-
infected men and women (Burack et al., 1993; Hudson, Lee, Miramontes & Portillo,
2001; Ickovics et al., 2001; Lee, Portillo & Miramontes, 2001; Linn et al., 1996) with
adequate internal consistency reliability (e.g., Cronbach alpha coefficient ranging from
.82 [Lee et al., 2001] to .87 [Burack et al., 1993]). The CES-D has also been used in
studies of HIV-infected pregnant women (Ethier et al., 2002; Ickovics et al., 2000) and
mothers (Bennetts et al., 1999; Johnson & Lobo, 2001; Lester, Partridge, Chesney &
Cooke, 1995; Miles, Gilliespie & Holditch-Davis, 2001; Miles, Holditch-Davis, Eron,
Black, Pedersen & Harris, 2003). Ethier and colleagues (2002) eliminated five items
from the CES-D that may reflect HIV-associated symptoms (e.g., fatigue) to reduce
confounding of the results. However, the majority of investigations conducted in HIV-
infected cohorts have used the CES-D 20-item scale. The CES-D scores for this sample
were calculated for both the complete 20-item scale and then again after excluding the
five somatic symptoms that might confound results. The Cronbach alpha coefficients
for the 20-item and the 15-item versions were both .94.

*Parental Perception of Uncertainty-Diagnosis (PPUS-D) Scale.* The PPUS-D
scale was developed to measure parental uncertainty during the diagnosis of HIV.
infection in children (Santacroce, 2000; Santacroce, 2001). The 25-item PPUS-D is based on the uncertainty in illness theory that includes four dimensions: ambiguity, unpredictability, lack of information, and lack of clarity (Mishel, 1981) and is a modification of Mishel's 31-item Parental Perceptions of Uncertainty Scale (PPUS) (Mishel, 1983).

The PPUS-D is a self-administered questionnaire with a 5-point Likert-type response format to score each item with values ranging from 1 ("strongly disagree") to 5 ("strongly agree"). Seven of the 25 items require reverse scoring. Total scores can range from 24 to 120, and higher scores indicate higher levels of uncertainty (Santacroce, 2001). The Cronbach alpha coefficient was .87 in a cross-sectional study of HIV-infected mothers when their infants (mean age = 30 weeks) were undergoing HIV diagnostic testing (Santacroce, 2000; Santacroce, 2001). The Cronbach alpha was .96 for this sample.

*Interpersonal Relationship Inventory Scale-Short Form (IPRI-SF).* The IPRI-SF is a shorter (26 items) version of the original 39-item IPRI, developed to evaluate social support, conflict in the social network, and the reciprocal “cost” of interpersonal relationships (Tilden, Nelson & May, 1990, p. 342). The IPRI-SF includes the social support and the conflict subscales, but does not include the reciprocity subscale reported to have equivocal validity and high correlation with the social support subscale (Kane & Day, 1999; Tilden, Nelson & May, 1990).

Items from the two subscales are intermingled throughout the instrument to decrease the likelihood of set response tendencies, and a Likert-type 5 point response format is used to score each item (Tilden, Nelson & May, 1990). Values for items 1
through 14 range from "strongly disagree" to "strongly agree" and for items 15 through 26 range from “often” to “never” with the totals for each subscale ranging from 13 to 65. Cronbach alpha coefficients range from .87 to .93 for social support and .80 to .91 for conflict in several different samples for psychometric testing of the instrument (Kane & Day, 1999; Tilden, Nelson & May, 1990). In addition, two-week test-retest reliability for social support and conflict subscales are reported to be 0.91 and 0.81, respectively (Tilden, Nelson & May, 1990). The Cronbach alpha coefficients for this sample were .98 and .95 for the social support and social network conflict subscales, respectively.

**Brief Symptom Inventory (BSI).** The Brief Symptom Inventory (BSI) is a self-administered questionnaire developed to measure current experiences of psychological distress (Derogatis & Melisaratos, 1983). Subjects are asked to rate how much they have experienced symptoms during the past week. There are 53 items that measure nine primary symptom dimensions to provide information about the type and intensity of a subject's distress, as well as delineate patterns of symptomatology (Derogatis & Melisaratos, 1983). Each item is rated on a Likert-type 5-point response format of distress ranging from 0 ("not-at-all") to 4 ("extremely") with a potential range of scores from 0 to 212 (Sharts-Hopko et al., 1996). The sum of these items is calculated, with higher scores reflecting more psychological distress. In addition, the global severity index (GSI) (designed to measure overall psychological distress using subscales of somatization, anxiety, and depression) can be calculated and is considered to be the best single indicator of current distress levels (Derogatis & Melisaratos, 1983).
Internal consistency and test-retest reliability have been evaluated in a variety of groups including pregnant and postpartum women (Otchet, Carey & Adam, 1999), and HIV infected patients (Sharts-Hopko et al., 1996). Internal consistency (Cronbach alpha) was above .70 for all dimensions (Derogatis & Melisaratos, 1983). Stability coefficients have been evaluated in healthy adults by administering the scale at a two-week interval. The test-retest reliability was .90 for the GSI (Derogatis & Melisaratos, 1983). The Cronbach alpha coefficient for the GSI in this sample was .92.

Use of this instrument to assess perceived psychological distress in HIV-infected women demonstrated a Cronbach alpha of .96 for the GSI (Hudson et al., 2001). In normal pregnant and postpartum women, the BSI has been shown to be more comprehensive in detecting psychological health status than the Short Form-36 Health Survey (Otchet et al., 1999).

Statistical Analysis

Descriptive statistics were determined for demographic variables. A two-tailed significance level of 0.05 with a 95% confidence interval was used for all analyses. Means and standard deviations were calculated for the total scores for each standardized scale. Correlations among variables were calculated using Pearson’s $r$, and repeated measures analysis of variance (RMANOVA) was used to test for significant change in the outcome measures over the 6 time points. Data were analyzed using the SPSS 11.5® statistical package.
Results

Between September 2004 and July 2006, 25 eligible HIV-infected pregnant women were approached and 21 enrolled in the study. One of the subjects was withdrawn from the study because it was determined that she was infected with a HIV clade (i.e., strain) that was not detected by viral assays currently available. As a result, there was no plan for her infant to undergo HIV viral testing and the infant would be tested using the standard HIV antibody test at 12 and 18 months of age. Of the remaining 20 women, two did not complete the final study visit (T3). The other 18 participants completed all six study visits.

Participants were primarily non-Hispanic Caucasian (40%) or non-Hispanic African American (40%). Women’s ages ranged from 19 to 43 years and years of completed education ranged from 10 to 20 years. The majority of the women were married (50%) or living with a partner (35%). Half of the women were employed at the time of entry into the study.

Forty percent of the participants had an AIDS diagnosis (a majority were given the diagnosis due to CD4 cell counts <200 without evidence of an opportunistic infection); 90% reported heterosexual transmission as the mode of acquiring HIV infection; and the majority (90%) were aware of their HIV infection status prior to this pregnancy (mean = 8.7 years; range 4 months – 24 years). The majority of women had undetectable viral loads and CD4 cell counts above 200 cells/mu at the time of enrollment (65% and 80%, respectively). All subjects were taking combination ARV’s during the pregnancy, with 75% of subjects planning to continue their ARV after
delivery to treat their HIV infection. Half of the 20 women reported that this pregnancy was unplanned. One of the births was preterm at 36 weeks gestation. Two years prior to study entry, one woman gave birth to an infected infant who died at 8 months of age due to AIDS complications; none of the other women had infected children.

The average weeks gestation at the time of enrollment (study visit T0) and the average number of days after birth that each postpartum study visit (T1A – T3) occurred are presented in Table 4.1. The majority of infants had their second HIV test performed 2 to 4 weeks after birth and their final viral test completed between 16 and 18 weeks of age. All of the infants were determined to be uninfected by HIV viral testing.

Table 4.2 presents the correlation matrix for the variables at the six study time points. Since the Cronbach’s alpha coefficient was the same for both the CES-D 20-item and 15-item scale (.94) we used the scores for the 20-item scale for our analysis. During the third trimester of pregnancy (T0), mean scores for depression, stress and distress were high (CES-D mean = 19.75 [SD = 14.8]; PSS-10 mean 16.45 [SD = 7.77]; GSI mean = 61.9 [SD = 8.70]). When depression was categorized according to the standard cutoff value for the CES-D in the general population (≥ 16), there were ten women with scores less than 16 (mean = 8.8, SD = 3.9, range 4 - 15) and ten with scores of 16 or greater (mean = 30.7, SD = 13.6, range = 18 - 52). Social support and social network conflict mean scores were 54.6 (SD = 11.9) and 35.5 (SD = 12.4), respectively, indicating a high degree of social support and a moderate degree of social network conflict in this sample. In addition, there was a significant positive correlation between social network conflict and depressive symptoms (r = .58, p <.01), social network conflict and distress (r = .51, p <.05), as well as frequency of depressive symptoms on
the CES-D and severity of distress on the GSI \((r = .70, p < .001)\). Social support demonstrated a significant inverse correlation with stress on the PSS \((r = -.79, p < .001)\), depressive symptoms on the CES-D \((r = -.65, p < .01)\), and distress on the GSI \((r = -.68, p < .001)\).

The relationships we observed during pregnancy for stress, distress, conflict and social support continued during the postpartum period. In addition there was a strong inverse relationship between social support and uncertainty starting at the study visit conducted just prior to the infant’s planned second HIV viral test \((T1A) (r = -.67, p < .001)\) that persisted through the final \((T3)\) study visit \((r = -.50, p < .05)\).

Figure 4.1 presents the results of the RMANOVA for changes over time of maternal perceptions of uncertainty, perceived stress, symptom distress, depressive symptoms, social support and network conflict during the postpartum study visits \((T1_{A,B}, T2_{A,B} \text{ and } T3)\). Maternal perceptions of uncertainty demonstrated a significant \((p < .001)\) decrease beginning just prior to the infants’ second HIV viral tests \((T1_A)\) until after the mothers received results from the infants’ 4 month viral test \((T2_B)\). There was also a significant decrease \((p = .035)\) in maternal perceptions of social network conflict immediately after receiving results of the infant’s second viral test \((T1_B)\) up to and including the final study visit \((T3)\). There were no significant decreases over time for maternal reports of stress, distress, depressive symptoms or social support.

Given the relatively high variance of depressive symptoms before delivery in half of the sample, we analyzed uncertainty about infant HIV serostatus after categorizing women into either a depressed \((\text{CES-D scores} \geq 16 \text{ prior to delivery}; n = 10)\) or non-depressed \((\text{CES-D scores} < 16; n = 10)\) group. Figure 4.2 presents the
changes in uncertainty over time with women in the depressed group showing significantly more uncertainty following a second negative infant HIV test result (T1B) compared to women in the non-depressed group ($p = .03$).

**Discussion**

This is the first study to investigate changes over time in maternal perceptions of stress, distress, social support, social network conflict and uncertainty about infant health in HIV-infected mothers during the period when the infant in undergoing HIV viral diagnostic testing. Our results indicate that there are high rates of stress, depression, and social network conflict in this cohort of HIV-infected women. This is consistent with previous reports about HIV-infected mothers and their experiences (Bennetts et al., 1999; Miles et al., 2001; Sharts-Hopko et al., 1996). In addition, the women in our study perceived moderately high levels of social support during the antepartum and postpartum periods.

Results demonstrate an overall significant decrease in maternal perceptions of uncertainty about infant HIV infection status as mothers proceed through the testing process of their infants. This finding suggests that each negative HIV viral test result for the infant further reinforces the likelihood that maternal HIV transmission did not occur during pregnancy or the intrapartum period, especially as the time of infant testing becomes progressively further distanced by several weeks and months from the last known HIV exposure date (i.e., 4 and 16 weeks after birth). In addition, women in this study reported moderate to high perceptions of social support which may have
contributed to their having a more positive outlook about their infant’s health status. HIV infected mothers’ perceptions of social support have been associated with decreased levels of uncertainty about infant HIV infection status and maternal health (Santacroce, 2000).

The mean depression score on the CES-D scale and percentage of women categorized as depressed in our group of participants at entry (50%) was higher than expected in the normal population but consistent with other studies that have systematically screened for depression in HIV-infected women. In a cohort of more than 1,000 HIV-positive women enrolled in the six-site national Women’s Interagency HIV Study, 54.4% were noted to have CES-D scores ≥ 16 (Cook et al., 2002). Johnson and Lobo (2001) conducted a cross-sectional study of HIV-infected mothers matched to uninfected mothers during the first year postpartum (mean = 10 months after birth). They found a higher percentage of depressive symptoms in the infected mothers (44%) compared to matched controls (20%) and a difference in mean CES-D scores for infected (18.6 +/- 12.4) compared to uninfected (10 +/- 7) for infected mothers. Miles and colleagues (2001) conducted a longitudinal study in 34 African American mothers of HIV-infected infants at 3, 6, 12, 18 and 24 months postpartum. Using CES-D scores of ≥ 16, they observed depressive symptoms in 32% to 41% of the mothers during the study.

Our study further documents higher frequencies of depressive symptoms during the third trimester of pregnancy and postpartum in HIV-infected women. Although the percent of postpartum women with depressive symptoms did decline in our study (from 45% at T1 to 33.3% at T3), this decrease was not found to be statistically significant in
this small sample. This finding is consistent with other investigators who observed declines in depressive symptoms from 41% at 6 months postpartum to 32% by 24 months postpartum in HIV-infected mothers period (Miles et al., 2001). However, it is important to note that the high frequency of depressive symptoms in our cohort continued for months after mothers learned that their infants were uninfected, suggesting an underlying basis for depression other than uncertainty about their infants’ HIV status. Although some symptoms associated with advanced HIV disease (e.g., fatigue, poor appetite) may confound assessments of depression, attributing depressive symptoms to HIV disease without proper clinical evaluation for depression places women at risk for adverse mental health outcomes. It has been well documented that maternal depression can negatively impact maternal-infant interactions, infant development, early childhood behaviors, and a mother’s ability to adhere to antiretroviral medications (Cook et al., 2007; Halligan, Murray, Martins & Cooper, 2007; Kalichman, Ramachandran & Catz, 1999; Philipps & O’Hara, 1991). In addition, depressive symptoms and negative affect has been associated with a decrease in survival in some cohorts of infected women and men (Ickovics et al., 2006; Moskowitz, 2003). Given the high percent of depression observed in different cohorts of HIV-infected women and a 13% to 35% prevalence of postpartum depression in uninfected women (Beeghly et al., 2003; McLennan, Kotelchuck & Cho, 2001), health care providers should be as vigilant in their screening for and treatment of depression as they are about HIV disease management.

We also observed a significant difference in the resolution of uncertainty between women who were depressed at study entry (T0) compared to those who were
not depressed. Depressed women continued to be more uncertain about their infants’ HIV infection status after they received results of the second viral test compared to non-depressed women. The difference between the groups of mothers’ resolution of uncertainty was not observed for study visits occurring around the infant’s four-month viral test. This may be an indication that a depressed mother needs more time to process the information she receives about her infant’s test results during the early postpartum period. For HIV-infected mothers, co-existing depression may exacerbate worry and concern about her health and the health of her infant, making it more difficult to appreciate or integrate the implications of a negative viral test result at that particular time. It may also represent maternal uncertainty about her own HIV infection. Maternal uncertainty about infant HIV diagnosis has been documented to influence an infected mother’s perception of uncertainty about her own health (Santacroce, 2000). In addition, it may be a reflection of depressed mothers feeling less hopeful about life in general, including the possibility that their infants may be infected despite negative test results. Finally, the physical demands of infant care taking and limited maternal sleep, especially during the first eight weeks postpartum, may be causing more cognitive impairment in the depressed mothers, further interfering with their ability to understand their infant’s HIV infection status. Cognitive impairment during the postpartum period has been reported in both uninfected and infected mothers; however, in infected mothers this impairment has been observed for longer periods (Kline, Martin & Deyo, 1998; Miles et al., 2001).

There was also a significant change in perceived social network conflict associated with the infant’s viral testing time points, with a decline evident as infant
HIV infection status was clarified for mothers over time. It is important to note that at the point in time when the mothers’ perceptions of social network conflict began to decrease (T2b), they had received at least three HIV negative viral test results. These changes may be due to a decreased need on the part of the mothers to seek social support from people who may simultaneously create discord or conflict in their lives.

No significant change over time was observed for maternal perceptions of stress, depressive symptoms and social support in association with infant viral testing. Despite the relief that mothers experience from learning that their infants are uninfected, the lack of change in these variables during the study period may represent the psychosocial milieu of the women’s lives regardless of the additional challenges that living with HIV infection poses, including awaiting the final HIV diagnosis for their infants. Chronic stress and depression, and the ability to identify and utilize resources are important elements involved in coping with daily life. Perceptions of stress and depressive symptoms may remain relatively constant for many women because they reflect the psychological or social environments that the women have dealt with for years (Miles, Holditch-Davis, Pedersen, Eron & Schwartz, 2007). In addition, the period of time that the mothers participated in the study may have been too short to measure decreases in perceptions of stress, distress, and depressive symptoms that might have occurred as a result of clinical interventions (e.g., psychotherapy) implemented during the study period.

There are a number of limitations of the study. The generalizability of our results is limited by the small sample size and the demographics of participants. In this study, 40% of the participants were African American while 64% of adolescents and
women living with HIV/AIDS identify as African American in nationally collected data (CDC, 2006b). While national surveillance data from anonymous reporting indicates that 72% of women identify heterosexual contact as the mode of HIV acquisition (CDC, 2006b), it was 90% in our sample. All of the study participants were engaged in prenatal and HIV-specialized care, were identified as being HIV-positive several months to years prior to delivery, and reported that they were the primary caretakers for their infants. Women who differ from these characteristics may experience different patterns of stress, distress, depression, social support and uncertainty about their infants’ health over time. In addition, women who are separated from their infants after birth (e.g., substance using women) may continue to experience uncertainty about their infants’ health if they are unable to obtain information about test results. Finally, the HIV medical expertise and community resources available in the San Francisco Bay Area may have influenced the results of this study. HIV-infected pregnant women living in other communities where resources are not as extensive may experience higher rates of stress and depression, as well as different patterns of resolution of uncertainty about their infants’ HIV infection status.

**Conclusion**

The findings of this prospective, longitudinal, repeated measures study indicate that HIV-infected women experience decreasing levels of uncertainty about the infection status of their infants as results from each HIV viral test are revealed. In addition, their perceptions about conflict within their social networks decline as they become more confident that their infants are not infected. While maternal perceptions
of stress, distress, depression and social support did not change over time in this study, the pattern of maternal resolution of uncertainty was affected by the presence of depressive symptoms during the third trimester of pregnancy. In addition, maternal perception of social support was associated with significantly less uncertainty throughout the testing period.

The results of this study also provide information about the timing of interventions to assist HIV-infected mothers during this stressful period. For example, acknowledging the stress associated with uncertainty about infant testing during pregnancy and postpartum may provide an opportunity for mothers to discuss their concerns. In addition, providing reassurance and quick responses to maternal questions and concerns about their infants’ health may reduce their experiences of psychological symptoms. Finally, despite the high likelihood of infants not being infected, the high prevalence of chronic depressive symptoms in this group of mothers underscores the need for ongoing assessment and initiation of interventions to treat this condition prior to and after they give birth.
Chapter 5.

Summary
Becoming a mother is regarded as a life long process that requires the successful adaptation and integration of psychosocial changes that occur in response to children’s and the family’s growth and development. The foundation of this process involves childbearing women’s attachment to their infants during pregnancy and early infancy. There are several factors that can alter a woman’s integration of the maternal role and establishment of a sound relationship with her infant, including maternal health status, infant health, psychological distress, and availability of social support (Mercer, 2004). For HIV-infected women, the process of assuming a maternal role during the first several months postpartum requires that they confront and successfully cope with complicated and unique issues such as clarifying the HIV infection status of their infants, administration of anti-HIV medications to their infants, and managing their own HIV disease.

This dissertation project was designed to investigate HIV-infected mothers’ experiences of uncertainty about infant HIV infection, stress, distress, depression and social support during the HIV viral testing of their infants due to a lack of information about these relationships in existing literature. There are a number of results from this project that contribute to a better understanding of these relationships and provide direction for future research and targeted clinical interventions to improve maternal and infant health outcomes.

This prospective, longitudinal, repeated measures study is the first to reveal that maternal perceptions of uncertainty about infant HIV infection status decline significantly over time in concert with the completion of each HIV viral test. However, differences in the trajectory of this decline were observed based on the presence or
absence of maternal depressive symptoms during the third trimester of pregnancy. Mothers with evidence of depressive symptoms prior to giving birth were more uncertain about the infection status of their infants after two negative test results were known (one result from testing completed within 2 days and one result from 2 to 4 weeks after birth) compared to mothers without depressive symptoms. Although both groups of mothers subsequently had similar declines in their perceptions of uncertainty, the significant difference between these groups at this point in the testing phase of their infants may indicate an alteration in the cognitive ability of depressed mothers to understand the implications of repeatedly negative test results for their infants. It is also possible that depressed mothers are less optimistic about the ultimate outcome for their infants and, therefore, they experience more uncertainty about the infant’s HIV infection status even in the presence of sequential negative viral tests.

Although maternal scores on the uncertainty scale declined significantly over time for the entire sample, a different profile for maternal perceptions about infant health emerged from content analysis of the qualitative data obtained at the same time as administration of the uncertainty scale. Rather than a continuous decline in identifying infant health issues as the most worrisome concern, the mothers’ responses revealed a more bimodal pattern about their major concerns. Just after results of the second HIV viral test were known, the percentage of mothers identifying infant health issues as being their major concern precipitously decreased from 80% \((n = 16)\) to 40% \((n = 8)\); however, the percentage of mothers citing this as a major concern rebounded to 55% \((n = 11)\) just prior to having the infant undergo the final HIV viral test. This pattern of maternal concern about infant health is understandable given that mothers
face yet another testing event in which they might be told the infant is infected, thereby
resurrecting maternal perceptions of uncertainty about infant health. This recurrent
heightened maternal concern about the infant just prior to HIV testing is one of the
reasons this study was proposed. However, the pattern of maternal worry about infant
health would not have been detected using standardized instruments, and underscores
the value of qualitative methods when exploring new areas of clinical research.

The results from the project revealed significant relationships among study
variables. During pregnancy, there were strong positive correlations between stress,
distress, depression and conflict within mothers’ social networks, and significant
inverse correlations between social support and these variables. These significant
associations persisted at several postpartum time points in the study. In addition,
maternal uncertainty about infant HIV diagnosis was also found to have similar strong
positive correlations with stress, distress, depression and social network conflict while
social support appeared to diminish the mother’s perception of uncertainty. This latter
finding is consistent with Santacroce’s (2000) observation that support, specifically that
provided by clinicians, was inversely correlated with maternal perceptions of
uncertainty about maternal and infant HIV.

In this cohort of twenty HIV-infected mothers, concern about infant health was
identified as the most worrisome issue when infants were undergoing HIV viral testing.
A distinct shift in maternal foci of concern away from infant health issues was
documented only after the result from the final viral test was known. Importantly, the
primary focus of maternal concern changed from infant health to other psychosocial
issues (e.g., having enough money to live, inadvertent disclosure of HIV infection,
personal problems with relatives or friends) but not maternal health issues. This lack of prioritization of maternal health issues during the first several months postpartum has not been previously described. A delay in focusing on maternal health issues may help explain why some HIV-infected mothers are unable to adhere to complex antiretroviral medication regimens or attend medical appointments that are necessary to monitor their disease progression after they give birth (Butz et al., 1993; Ickovics et al., 2001). In addition, the sleep deprivation that is associated with infant care-taking responsibilities combined with the prolonged postpartum impairment of cognitive functioning reported in HIV-infected mothers may be contributing to maternal alterations in perceptions of what are truly critical issues (particularly those addressing maternal health), as well as simply forgetting about scheduled health care appointments (Miles, Gillespie & Holditch-Davis, 2001). Similar to previous investigations (D’Auria, Christian & Miles, 2006; DeMatteo, Wells, Goldie & King, 2002; Faithfull, 1997; Sandelowski & Barroso, 2003), even when maternal health issues were identified as a major concern, the mothers in this study often cited the importance of maintaining their health in order to take care of the infant and other children.

For the majority of mothers in this study, perceptions about their infants’ HIV testing process were associated with negative connotations throughout most of the testing. In addition, a third of the mothers continued to report negative perceptions several weeks after HIV viral testing was completed and the infant was determined to be uninfected. Previous qualitative studies conducted in HIV-infected mothers have documented similar perspectives about infant testing, but none have recorded maternal perceptions about infant testing over time. Maternal explanations about the negative
connotations about the infant’s testing process reflected a combination of maternal guilt associated with the need for infant testing as well as psychological distress due to infant discomfort the mothers witnessed during the phlebotomies performed on their infants. It is unknown how long maternal guilt and psychological distress about the infant testing process may persist, or whether it may resolve but recur in response to other procedures an infant may normally experience as part of routine pediatric primary care (e.g., immunizations). It is possible that some mothers are reliving their own experiences of having HIV testing done, as well as confronting the fact that they must continue to undergo this process at regular intervals to monitor progression of their own disease. For a mother who has difficulty with her own phlebotomy procedures, witnessing her infant’s specimen collection may be physically and emotionally draining. However, a simple solution may be to offer mothers the option to wait in a separate room to avoid having to witness the infant’s phlebotomy. Some mothers may be reluctant to do this, but others may welcome the chance to physically, and possibly emotionally, distance themselves from this event.

Mothers’ negative perceptions about the infant testing process, coupled with uncertainty about the infant’s HIV status, raises concerns about the potential for the development of aberrant maternal-infant relationships and the vulnerable child syndrome. Consistent with reports from previous studies (Ingram & Hutchinson, 1999; Sandelowski & Barroso, 2003), mothers in this sample expressed ongoing concerns about the possible risk of HIV infection for their infants, even after the infants were determined to be uninfected. Some of this may be caused by the mother’s realization that, although her infant completed all recommended viral tests, the infant must still
undergo HIV antibody testing at 12 or 18 months of age to document loss of maternal HIV IgG antibodies. The contradictory nature of the message that is being given to these mothers about their infants’ need for further testing, even though the infant is considered to be HIV negative, could lead to maternal misunderstanding about the true infection and health status of her infant. Mothers of newborns who were hospitalized for the treatment of uncomplicated physiologic jaundice were documented to have higher rates of perceptions of medical vulnerability in their infants, as well as aberrant maternal-infant relationships that persisted for several months after the hospitalization (Kemper, Forsyth & McCarthy, 1989; Kemper, Forsyth & McCarthy, 1990). It is possible that mothers of perinatally-exposed, HIV uninfected infants may be at an increased risk of perceiving their child as being more vulnerable to medical problems. In addition, chronic maternal worry and stress about the health of a child may contribute to “stress aging” of the woman causing her to be physiologically older than her chronological age (Epel et al., 2004). For HIV-infected mothers, premature aging could contribute to an increased risk of complications associated with their HIV infection, adverse effects of antiretroviral medications (e.g., hyperlipidemia, cardiovascular disease), and early death.

The mothers in this study demonstrated a high rate of depressive symptoms, similar to other cohorts of HIV-infected pregnant and non-pregnant women (Cook et al., 2002; Johnson & Lobo, 2001; Miles et al., 2001). During pregnancy, 50% of the women in this study reported depressive symptoms using the Center for Epidemiologic Studies – Depression (CES-D) 20-item scale with a standard cutoff value of ≥ 16. Depression has been associated with significant declines in CD4 cell counts and
increased mortality in HIV-infected women and men (Ickovics et al., 2001; Ickovics et al., 2006; Moskowitz, 2004). In addition, stress and depression in mothers has been documented to alter normal maternal-child relationships and contribute to psychological and behavioral problems in children (Guttleling et al., 2005; Halligan et al., 2007; Moehler et al., 2006). For HIV-infected mothers, the long-term effects of psychological distress, especially depression, on their relationship with their children is unknown. It is important for mothers who indicate significant depressive symptoms through responses to standardized depression scales be evaluated clinically with initiation of therapeutic interventions as indicated.

Generalizability of the findings from this dissertation project are limited due to a number of factors including the small sample size, the fact that all of the mothers were engaged in pregnancy and HIV-specialized care, and the availability of extensive health and community-based resources for their use. It is possible that this study underestimates the magnitude of some of the findings, especially in HIV-infected mothers who are not receiving comprehensive HIV care.

The major findings of the study, specifically maternal uncertainty, depression and lack of focus on maternal health issues can be addressed through clinical interventions that might substantially assist mothers during this difficult period of time. Addressing the subject of infant testing and medications during prenatal visits would afford women the opportunity to think about and articulate their concerns prior to the birth. Assessing women for psychological symptoms that require interventions during pregnancy, as well as educating women about the signs and symptoms of depression offers an opportunity for early treatment of these conditions and may reduce the
likelihood of an exacerbation of symptoms after birth. Arranging for a 2-week maternal postpartum visit with the mother’s primary care provider (e.g., HIV specialist) would allow for formal screening for psychological symptoms possibly requiring initiation of therapeutic interventions, assessment of adherence to HIV specific medications for those women continuing these therapies, and evaluation of other socioeconomic issues that may have emerged or worsened since the birth. In situations where a clinical visit is not possible, telephone contact with the mother by her clinician or a social worker to assess these situations is another option. In clinical settings where there are different clinicians responsible for the care of the mothers and the infants, pediatric health care providers can directly assess maternal concerns about their infants, as well as evaluate the mothers for evidence of psychological stress or distress. Specifically asking mothers about how they are doing with their medications and clinical appointments may also identify those women who are in need of interventions to assist them with their health needs.

Finally, there are several future research studies that could be designed to further enhance our knowledge and improve the clinical care of HIV-infected mothers as a result of this project including: 1) a larger study with multiple centers to determine the magnitude of uncertainty, stress, and depression in other cohorts of mothers; 2) evaluating the relationship between uncertainty about fetus/infant HIV serostatus and maternal attachment during pregnancy and for the first several months postpartum; 3) randomized clinical trial assigning women to standard pregnancy and postpartum care compared to a “centering pregnancy” model of care to determine if there is a difference in experience of uncertainty, stress, distress, social support, and adherence to maternal
therapies; 4) expanding length of study to follow mothers and infants for up to five years to evaluate the maternal-infant relationship and development of the vulnerable child syndrome; 5) psychometric evaluation of different depression scales (e.g., Edinburgh Depression Scale, Postpartum Depression Screening Scale 7-item and 35-item, Center for Epidemiologic Studies-Depression Scale) to determine which might be most appropriate for use in HIV-infected pregnant and postpartum mothers; and 6) evaluating perceptions of uncertainty, stress, depression and social support in pregnant and postpartum women with other types of chronic diseases (e.g., hepatic C, hemoglobinopathies) and compare these with HIV-infected women’s experiences.
References


Kane, R. T., & Day, C. (1999). The psychometric characteristics of the IPR inventory: Data from rural Western Australia. *Nursing Research, 48*, 324-328.


## Table 2.1 Stress Mediators and Changes Observed During Normal Pregnancy

<table>
<thead>
<tr>
<th>Allostatic Biomarker</th>
<th>Changes During Pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adrenocorticosteroid hormone</td>
<td>Increased maternal plasma and fetal levels during the second and third trimesters</td>
</tr>
<tr>
<td>Cortisol</td>
<td>Increased maternal plasma and fetal levels during the second and third trimesters</td>
</tr>
<tr>
<td>Corticotropin-releasing hormone</td>
<td>Increased maternal plasma levels during the second and third trimester</td>
</tr>
<tr>
<td></td>
<td>Derived from placenta (trophoblastic cell CRH gene expression)</td>
</tr>
<tr>
<td>Norepinephrine and epinephrine</td>
<td>No changes from prepregnancy maternal levels</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>Lower systolic and diastolic levels in the second and third trimesters</td>
</tr>
<tr>
<td>Heart rate reactivity</td>
<td>Diminished reactivity noted during the third trimester of pregnancy and in lactating women</td>
</tr>
</tbody>
</table>

Table 2.2  Examples of Allostatic Mediators Reflecting Acute and Chronic Stress Responses

<table>
<thead>
<tr>
<th>Measures of Acute Stress Responses</th>
<th>Measures of Chronic Stress Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adrenocorticosteroid hormone</td>
<td>Cardiovascular activity</td>
</tr>
<tr>
<td>Cortisol</td>
<td>Waist-hip ratio</td>
</tr>
<tr>
<td>Corticotropin-releasing hormone</td>
<td>Serum high-density lipoprotein and total cholesterol</td>
</tr>
<tr>
<td>Epinephrine (E) and norepinephrine (NE)</td>
<td>Plasma glycosylated hemoglobin</td>
</tr>
<tr>
<td>Cardiovascular reactivity (e.g., BP)</td>
<td>Overnight urinary cortisol, E and NE excretion</td>
</tr>
</tbody>
</table>

Table 3.1 Questions About Maternal Issue(s) of Concern

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which among the following is a concern for you now? (woman can select as many responses that she feels applies)</td>
<td>Maternal Health Related:</td>
</tr>
<tr>
<td></td>
<td>• Your HIV infection</td>
</tr>
<tr>
<td></td>
<td>• Your HIV medications</td>
</tr>
<tr>
<td></td>
<td>• Your pregnancy**</td>
</tr>
<tr>
<td></td>
<td>• Having a safe birth without problems**</td>
</tr>
<tr>
<td>Fetus/Baby Health Related:</td>
<td>• Transmitting HIV infection to your baby</td>
</tr>
<tr>
<td></td>
<td>• The health of your baby</td>
</tr>
<tr>
<td></td>
<td>• Your baby’s HIV medications</td>
</tr>
<tr>
<td>Other:</td>
<td>• Disclosure of your HIV infection to someone you don’t want to know about it</td>
</tr>
<tr>
<td></td>
<td>• Disclosure of your infant’s HIV testing to someone you don’t want to know about it</td>
</tr>
<tr>
<td></td>
<td>• Having enough money to live</td>
</tr>
<tr>
<td></td>
<td>• Guardianship for your baby after he/she is born</td>
</tr>
<tr>
<td></td>
<td>• Your husband/partner leaving you</td>
</tr>
<tr>
<td></td>
<td>• Having your baby taken away to live with someone else (e.g., Child Protective Services)</td>
</tr>
<tr>
<td></td>
<td>• Personal problems with relatives or friends</td>
</tr>
<tr>
<td></td>
<td>• Other concerns (please specify)</td>
</tr>
<tr>
<td>Which one of the issues above (i.e., in the previous question) worries you the most?</td>
<td>• Woman chooses from her selected responses to the previous question.</td>
</tr>
<tr>
<td>Would you write down or tell me selection. why that is the most worrisome for you?</td>
<td>• Woman describes the reason for her selection.</td>
</tr>
</tbody>
</table>

* Responses were randomly ordered to reduce response bias
** Question only asked during antepartum study visit
Table 3.2 Sociodemographic Data of the Sample at Entry

<table>
<thead>
<tr>
<th>Variable</th>
<th>n = 20 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age</td>
<td>32.25 years (range = 19 – 43 years)</td>
</tr>
<tr>
<td>Racial/Ethnic Background:</td>
<td></td>
</tr>
<tr>
<td>Black (non-Hispanic)</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>White (non-Hispanic)</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Native American</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Education Level (number of years completed)</td>
<td>14.5 years (range = 10 – 20 years)</td>
</tr>
<tr>
<td>Income (average monthly household prior to taxes)</td>
<td>$4033.50    (median = 2,650; range = $500 - $10,000)</td>
</tr>
<tr>
<td>Marital Status:</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Single (never married)</td>
<td>7 (35%)</td>
</tr>
<tr>
<td>Living with partner</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Occupational Status</td>
<td></td>
</tr>
<tr>
<td>Employed – full time</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>Employed – part time</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>HIV Disease Stage:</td>
<td></td>
</tr>
<tr>
<td>HIV Infection</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>AIDS</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>Transmission Risk:</td>
<td></td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>18 (90%)</td>
</tr>
<tr>
<td>Transfusion recipient</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Perinatal exposure</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Primigravida</td>
<td>7 (35%)</td>
</tr>
<tr>
<td>Multigravida</td>
<td>13 (65%)</td>
</tr>
<tr>
<td>Average Number of Living Children (including infant born after enrollment in study)</td>
<td>2.2 children (median = 2; range = 1 – 6)</td>
</tr>
<tr>
<td>Gestational Age at Birth for Current Pregnancy:</td>
<td></td>
</tr>
<tr>
<td>Term (≥ 37 weeks gestation)</td>
<td>19 (95%)</td>
</tr>
<tr>
<td>Pre-term (&gt;32 - &lt; 37 weeks gestation)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Mode of Childbirth</td>
<td></td>
</tr>
<tr>
<td>Vaginal birth</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Cesarean birth</td>
<td>10 (50%)</td>
</tr>
</tbody>
</table>
Table 4.1  Study Visit Schedule for Time Points T0 – T3

<table>
<thead>
<tr>
<th></th>
<th>T0 (Weeks Gestation) n = 20</th>
<th>T1&lt;sub&gt;A&lt;/sub&gt; (Days After Birth) n = 20</th>
<th>T1&lt;sub&gt;B&lt;/sub&gt; (Days After Birth) n = 20</th>
<th>T2&lt;sub&gt;A&lt;/sub&gt; (Days After Birth) n = 20</th>
<th>T2&lt;sub&gt;B&lt;/sub&gt; (Days After Birth) n = 20</th>
<th>T3 (Days After Birth) n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>34.95 (2.06)</td>
<td>15.75 (5.98)</td>
<td>35.05 (10.41)</td>
<td>121.85 (7.69)</td>
<td>150.15 (30.76)</td>
<td>221.22 (52.32)</td>
</tr>
<tr>
<td>Median</td>
<td>34.5</td>
<td>14</td>
<td>29.5</td>
<td>121.5</td>
<td>143</td>
<td>201</td>
</tr>
</tbody>
</table>

T0:  Third trimester of pregnancy
T1<sub>A</sub>: Prior to infant’s second HIV viral test
T1<sub>B</sub>: After maternal receipt of infant’s second HIV viral test result
T2<sub>A</sub>: Prior to infant’s final HIV viral test
T2<sub>B</sub>: After maternal receipt of infant’s final HIV viral test result
T3:  At least 4 weeks after maternal receipt of infant’s final HIV viral test result
Table 4.2 Correlation Matrix: T0 – T3 Visits

### T0 (n=20)

<table>
<thead>
<tr>
<th></th>
<th>PSS-10</th>
<th>CES-D</th>
<th>BSI-GSI</th>
<th>IPRI-SS</th>
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### T1A (n=20)

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### T2B (n=20)

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### T3 (n=18)

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*p < .05  ** p < .01  *** p < .001
Figure 2.1. Types of Allostatic Responses

The top panel illustrates the normal allostatic response to a stressor where the response is sustained for an appropriate interval followed by a recovery phase. The remaining panels illustrate four conditions that lead to allostatic load: repeated “hits” from multiple stressors; repeated hits with lack of adaptation; prolonged response as a result of a delayed recovery or shutdown; and inadequate response that leads to compensatory hyperactivity of other mediators (e.g., inadequate secretion of glucocorticoids resulting in increased concentrations of cytokines).

Figure 3.1 Percent of Mothers Ever Identifying An Issue of Concern

Maternal HIV = concern about maternal HIV infection
Baby’s health = concern about the health of the baby
HIV Transmission = HIV transmission from mother to fetus/infant
Birth = concern about having a safe birth without problems (antepartum visit only)
Disclosure (B) = concern about disclosure of infant HIV testing/medications to someone the mother does not want to know about it
Money = concern about having enough money to live
Pregnancy = concern about the pregnancy (antepartum visit only)
Disclosure (M) = concern about disclosure of maternal HIV infection to someone the mother does not want to know about it
Baby ARV = concern about infants HIV medications
Maternal ARV = concern about mother’s HIV medications
Guardianship = concern about guardianship for infant after birth
Abandonment = concern about spouse/partner leaving
Child removal = concern about the infant being taken to live with someone else
Other = concern about an issue not listed
Figure 3.2 Mothers’ Most Worrisome Concern Over Time (T0 – T3)

- **T0 (n = 20):** Third trimester visit (mean = 35 weeks gestation)
- **T1A (n = 20):** Infant’s second HIV viral test (mean = 16 days after birth)
- **T1B (n = 20):** Within 1 – 2 weeks of mother’s receipt of infant’s second HIV viral test result
- **T2A (n = 20):** Infant’s final HIV viral test (mean = 17 weeks after birth)
- **T2B (n = 20):** Within 1 – 2 weeks of mother’s receipt of infant’s final HIV viral test result
- **T3 (n = 18):** At least 4 weeks after maternal receipt of infant’s final clinical viral test (mean = 32 weeks after birth)
Figure 3.3  Emotional Valence of Maternal Single Word Description of Infant HIV Viral Testing Process Over Time (T0 – T3)

T0 (n = 20): Third trimester visit (mean = 35 weeks gestation)
T1A (n = 20): Infant’s second HIV viral test (mean = 16 days after birth)
T1B (n = 20): Within 1 – 2 weeks of mother’s receipt of infant’s second HIV viral test result
T2A (n = 20): Infant’s final HIV viral test (mean = 17 weeks after birth)
T2B (n = 20): Within 1 – 2 weeks of mother’s receipt of infant’s final HIV viral test result
T3 (n = 18): At least 4 weeks after maternal receipt of infant’s final clinical viral test (mean = 32 weeks after birth)
Figure 4.1 Maternal Postpartum Perceptions of Stress, Distress, Depression, Uncertainty, Social Support and Social Network Conflict Over Time (n = 18)

- **T1A**  
- **T1B**  
- **T2A**  
- **T2B**  
- **T3**

<table>
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<th>Study Time Point</th>
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<td>GSI (ns)</td>
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<td>PPUS-D (p&lt;.001)</td>
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<td>IPRI-SS (ns)</td>
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<tr>
<td></td>
<td>IPRI-C (p=.035)</td>
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</table>

**PSS-10**: Perceived Stress Scale-10 Items  
**GSI**: Global Severity Index of the Brief Symptom Inventory  
**CES-D**: Center for Epidemiologic Studies – Depression  
**PPUS-D**: Parental Perceptions of Uncertainty - Diagnosis Scale  
**IPRI-SS**: Interpersonal Relationship Inventory - Social Support  
**IPRI-C**: Interpersonal Relationship Inventory - Social Network Conflict
Figure 4.2 Maternal Postpartum Perceptions of Uncertainty Over Time by Depressive Symptoms at Entry

Study Time Points (* p = .03)
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