# ORIGINAL CONTRIBUTION

# HIV-infected mothers' perceptions of uncertainty, stress, depression and social support during HIV viral testing of their infants

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Abstract To explore relationships between mothers' uncertainty about infant HIV serostatus with stress, distress, depressive symptoms, and social support during infant HIV testing. This prospective longitudinal study of 20 HIVinfected mothers involved a prenatal visit and five postpartum visits clustered around infant HIV viral testing. Maternal uncertainty about infant HIV serostatus significantly decreased over time (p<0.001). Before testing, uncertainty was inversely related to social support (r=-0.67), and positively related to perceived stress (r=0.54), interpersonal social conflict (r=0.57), symptom distress (r=0.62), and depressive symptoms (r=0.50); these relationships persisted throughout the infant testing period. Mothers with depressive symptoms during pregnancy demonstrated significantly more uncertainty within a few weeks after birth than mothers without depressive symptoms (p < 0.05). Several weeks after learning their infants were HIV negative, mothers' uncertainty was only associated with social conflict (r=0.49). Maternal uncertainty about infant HIV status declined significantly over time. There were no changes in perceptions of stress, distress or social support. Mothers with depressive symptoms experienced greater uncertainty about infants' HIV status. Strategies to enhance support and treat depressive symptoms may reduce the uncertainty, stress, and distress HIV-infected mothers experience during viral testing of their infants.

**Keywords** HIV-infected · Postpartum · Stress · Depression · Uncertainty

## Introduction

In the United States (U.S.), an estimated 7,000 to 8,000 HIV-infected women give birth each year (Centers for Disease Control and Prevention [CDC] 2006). The number of perinatally HIV-infected infants declined from a peak incidence of 1,650 per year in 1991 to less than 250 per year in 2002 (CDC 2006). 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

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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 et al. 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 et al. 2006).

There is limited information that addresses the HIVinfected 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 et al. 1997; Santacroce 2000; Sharts-Hopko et al. 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 antiretroviral 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 2% 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 polymerase chain reaction (PCR) 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 or 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, their perceptions of stress, symptom distress, frequency of depressive symptoms, and level of social support and social conflict during the HIV viral testing process of their perinatally exposed infants.



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 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 during a face-to-face visit with the investigator. All documents were stored in a locked filing cabinet that was accessible only to the first author.

# Study design

This prospective, longitudinal study was conducted from Sept 2004 through June 2007. Participants had a total of six visits; one during the third trimester of pregnancy (T0), and five subsequent visits after delivery. After delivery, HIVinfected 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 were timed to capture data about maternal perceptions and concerns associated with the infant's second HIV viral test (T1<sub>A</sub>) and its result (T1<sub>B</sub>), and the infant's 16 to 24 week HIV viral test (T2A) and its result (T2<sub>B</sub>). 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. The final visit (T3) was conducted at least four weeks after the final HIV viral test result was received by the mother (T2<sub>B</sub>), and occurred at a time other than when infant medical appointments for routine pediatric care (e.g., immunizations) were planned.

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



levels of uncertainty, stress, symptom distress, depressive symptoms, and social support and are further described below. Although the terms "stress" and "distress" are often used interchangeably in the literature, parsimonious definitions of these concepts were considered in order to select appropriate instruments to measure these variables in this study. Stress refers to a person's perception of demands (both internal and external) that taxes or exceeds adaptive capacity (Cohen and Williamson 1988; Lazarus and Folkman 1984). Distress is an individual's response (psychological or physiological) to perceived stress (Cohen and Williamson 1988; McEwen 1998).

#### Instruments

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). We measured maternal perceptions of uncertainty using this scale. 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 five-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 0.87 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 0.96 for this sample.

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 et al. 1983, p. 386; Cohen and Williamson 1988, p. 33). It uses a Likert-type five-point response format that ranges from 0 ("never") to 4 ("very often"). Reverse scoring is used for four of the ten items and are 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=0.78) (Cohen and Williamson 1988). The Cronbach alpha coefficient for this sample was 0.90.

Center for Epidemiological Studies-Depression (CES-D) scale The CES-D is a self-administered depression screen-

ing tool developed to estimate the frequency of depressive symptoms in the general population (McDowell and 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 and Newell 1996). It uses a Likert-type four-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 4 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 and Newell 1996; Radloff 1977). Cronbach alpha coefficients range from 0.85 for samples from the general population to 0.90 for patient samples (McDowell and Newell 1996, p. 255; Radloff 1977, p. 387).

The CES-D has been used in several studies investigating depressive symptoms in HIV-infected men and women (Burack et al. 1993; Hudson et al. 2001; Ickovics et al. 2001; Lee et al. 2001; Linn et al. 1996) with adequate internal consistency reliability (e.g., Cronbach alpha coefficient ranging from 0.82 [Lee et al. 2001] to 0.87 [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 and Lobo 2001; Lester et al. 1995; Miles et al. 2001; Miles et al. 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 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 0.94.

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 et al. 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 and Day 1999; Tilden et al. 1990).

Items from the two subscales are intermingled throughout the instrument to decrease the likelihood of set response tendencies, and a Likert-type five point response format is used to score each item (Tilden et al. 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 0.87 to 0.93 for social support and 0.80 to 0.91 for conflict in several different samples for psychometric testing of the instrument (Kane and Day 1999; Tilden et al. 1990). In addition, 2-week test—retest reliability for social support and conflict subscales is reported to be 0.91 and 0.81, respectively (Tilden et al. 1990). The Cronbach alpha coefficient for this sample was 0.98 for social support and 0.95 for social network conflict.

Brief Symptom Inventory (BSI) The Brief Symptom Inventory (BSI) is a self-administered questionnaire developed to measure current experiences of psychological symptom distress (Derogatis and 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 and Melisaratos 1983). Each item is rated on a Likert-type five-point response format of distress ranging from 0 ("nota-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 and Melisaratos 1983).

Internal consistency and test–retest reliability have been evaluated in a variety of groups including pregnant and postpartum women (Otchet et al. 1999), and HIV-infected patients (Sharts-Hopko et al. 1996). Internal consistency (Cronbach alpha) was above 0.70 for all dimensions (Derogatis and Melisaratos 1983). Stability coefficients have been evaluated in healthy adults by administering the scale at a 2-week interval. The test–retest reliability was 0.90 for the GSI (Derogatis and 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 0.96 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 six 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; four declined participation. One was withdrawn from the study because she was infected with a HIV clade (i.e., strain) 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, one did not complete the final visit (T3). The other 19 participants completed all six 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 were married (50%) or living with a partner (35%) and half 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 (65%) and CD4 cell counts above 200 cells/mu (80%) at the time of enrollment. All participants were taking HAART doses during the pregnancy, and 75% planned to continue their HAART medications after delivery. Half of the 20 women reported that this pregnancy was unplanned. One birth 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 others had infected children.

The average weeks of gestation at the time of enrollment (study visit T0) and the average number of days after birth for each postpartum visit ( $T1_A$ –T3) are presented in Table 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 with HIV based on their final viral test result.



Table 1 Study visit schedule for time points T0-T3

	T0 (weeks gestation) <i>n</i> =20	T1 <sub>A</sub> (days after birth) $n=20$	$T1_B$ (days after birth) $n=20$	$T2_A$ (days after birth) $n=20$	$T2_B$ (days after birth) $n=20$	T3 (days after birth) <i>n</i> =19
Mean (SD)	34.95 (2.06)	15.75 (5.98)	35.05 (10.41)	121.85 (7.69)	150.15 (30.76)	221.22 (52.32)
Median	34.5	14	29.5	121.5	143	201
Range	32–39	9–35	26–59	140	129–273	168–336

T0 Third trimester of pregnancy,  $T1_A$  prior to infant's second HIV viral test,  $T1_B$  after maternal receipt of infant's second HIV viral test result,  $T2_A$  prior to infant's final HIV viral test,  $T2_B$  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

Since the Cronbach alpha coefficient was determined to be the same for both the CES-D 20-item and 15-item scale (0.94), the 20-item scale was used for this analysis. During the third trimester (T0), scores for depressive symptoms, stress and distress were high (CES-D=19.8±14.8; PSS-10=  $16.5\pm7.8$ ; GSI= $61.9\pm8.7$ ). When depressive symptoms were categorized according to the CESD standard cutoff value for the general population ( $\geq 16$ ), there were ten women with scores less than 16 (8.8±3.9, range four 15) and ten with scores of 16 or greater (30.7 $\pm$ 13.6, range 18–52). Social support and social network conflict scores were 54.6±11.9 and 35.5±12.4, respectively, indicating a high degree of social support and a moderate degree of social network conflict. In addition, high social network conflict was associated with depressive symptoms (r=0.58, p<0.01) and symptom distress (r=0.51, p<0.05). Social support was inversely correlated with perceived stress (r=-0.79, p<0.001), depressive symptoms (r=-0.65, p<0.01), and symptom distress (r=-0.68, p<0.001).

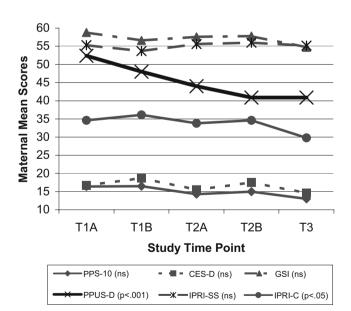
During the postpartum period, the relationships between uncertainty and stress, symptom distress, depressive symptoms, social conflict and support remained similar to those observed during the antepartum period. In addition there was a strong inverse relationship between uncertainty and social support starting at the study visit conducted just prior to the infant's planned second HIV viral test (T1<sub>A</sub>) (r=-0.67, p<0.001) that persisted until after the mothers received the results from the infants' final HIV viral test (T2<sub>B</sub>) (r=-0.50, p<0.05), and a strong positive relationship between uncertainty and social conflict (T1<sub>A</sub> r=0.57, p<0.01; T2<sub>B</sub> r=0.54, p<0.05).

Figure 1 presents the results of the RMANOVA for change over time in maternal perceptions of uncertainty, perceived stress, symptom distress, depressive symptoms, social support and network conflict during the postpartum visits. The PPUS-D has not been validated for use in pregnancy, therefore, it was not administered during the antepartum visit. Maternal perceptions of uncertainty demonstrated a significant (p< 0.001) decrease beginning just prior to the infants' second HIV viral tests (T1<sub>A</sub>) until after the mothers received results from the infants' 4-month viral test (T2<sub>B</sub>). There was also a significant decrease (p<0.05) 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 changes over time for maternal reports of stress, symptom distress, depressive symptoms, or social support.

Given the relatively high variance of depressive symptoms before delivery, uncertainty about infant HIV serostatus was also analyzed after categorizing women into either a depressed (CES-D scores  $\geq 16$  prior to delivery; n=10) or non-depressed (CES-D scores < 16; n=10) group. Figure 2 presents the changes in uncertainty over time, with women in the depressed group having more uncertainty following a second negative infant HIV test result (T1<sub>B</sub>) compared to women in the non-depressed group (p=0.03).

Analyses were also conducted to determine whether having planned the pregnancy influenced mothers' perceptions of uncertainty, depressive symptoms and symptoms of



**Fig. 1** Maternal perceptions of stress, distress, depression, uncertainty, social support and social network conflict over time (*n*=19). *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

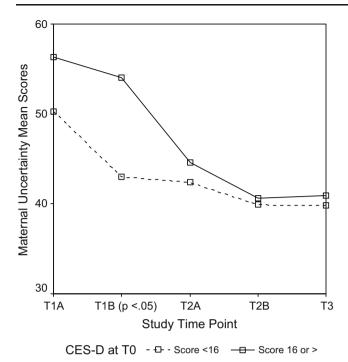


Fig. 2 Maternal perceptions of uncertainty over time by depressive symptoms at entry

stress and distress. Results revealed that the mothers who did not plan this pregnancy had significantly higher perceptions of stress (p<0.05) and depressive symptoms (p<0.05) than mothers who planned the pregnancy.

# Discussion

This is the first study to investigate changes over time in maternal perceptions of uncertainty about infant health associated with perceived stress, symptom distress, social support, social network conflict and depressive symptoms in HIV-infected mothers during the period when infants are undergoing HIV viral diagnostic testing. Results indicate that there are high rates of stress, depressive symptoms, 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). These women also perceived moderately high levels of social support during the antepartum and postpartum periods.

Results demonstrate an overall significant decrease in maternal uncertainty about infant HIV infection status as they proceeded through the testing process. This suggests that each negative viral test result further reinforced the likelihood that maternal HIV transmission did not occur, especially as the time of testing became progressively distanced by weeks and months from the last known HIV exposure date. In addition, women reported moderate to

high 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).

Depression scores on the CES-D and percentage of women categorized as having an increased frequency of depressive symptoms in this sample 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. They found a higher rate of depressive symptoms in infected mothers (44%) compared to matched controls (20%) and a difference in CES-D scores for infected (18.6±12.4) compared to uninfected (10 $\pm$ 7) mothers. Miles and colleagues (2001) conducted a longitudinal study in 34 African American mothers of HIVinfected infants at five time points until 24 months postpartum and found 32% to 41% of the mothers were categorized as having an increased frequency of depressive symptoms (using a CES-D scores of ≥16) at some point during the study.

Our study further supports other research on the higher frequency of depressive symptoms during the third trimester of pregnancy and postpartum in HIV-infected women. Although the rate declined (from 45% at T1<sub>A</sub> to 33.3% at T3), this decrease from 9 to 7 women was not statistically significant in this small sample. It is consistent with others who also observed cases of depression drop from 41% at 6 months postpartum to 32% by 24 months postpartum in HIV-infected mothers (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 depressive symptoms unrelated to uncertainty about their infants' HIV status.

Although some symptoms associated with advanced HIV disease (e.g., fatigue, poor appetite) may confound assessment of depression, attributing depressive symptoms to HIV disease without proper clinical evaluation for depression places women and their infants 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 et al. 2007; Kalichman et al. 1999; Philipps and O'Hara 1991). In



addition, depressive symptoms have 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, health care providers should be as vigilant in screening for depression as they are in HIV disease management.

A significant difference in the resolution of uncertainty between women who had a high frequency of depressive symptoms at study entry (T0) compared to those who did not have a high frequency of depressive symptoms was observed in this study. Women with higher CES-D scores continued to be more uncertain about their infants' HIV infection status after they received the second viral test result compared to women with lower CES-D scores. This difference was not observed at the infant's 4-month viral test (T2A). 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 the mother's 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 a depressed mother feeling less hopeful about her life in general, including the possibility that her infant may be infected despite negative test results. Finally, the physical demands of infant care taking and limited sleep, especially during the first 8 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. This impairment has been observed to persist for longer periods in infected mothers (Kline et al. 1998; Miles et al. 2001).

There was also a significant decline in perceived social network conflict associated with the infant's viral testing as infant HIV infection status was clarified for mothers over time. It is important to note that when the mothers' perceptions of social network conflict began to decrease  $(T2_B)$ , they had received at least three negative test results. These changes may be due to less need on the part of the mothers to seek social support from people who may simultaneously create discord or conflict in their lives.

Women in the study who experienced an unplanned pregnancy reported higher perceived stress and depressive symptoms compared to women with planned pregnancies. This finding supports other studies on the relationship between unplanned pregnancies and stress and depression in uninfected women (Bowen and Muhajarine 2006; Lau

and Keung 2007). However, it is unclear if women in this study were experiencing stress and depressive symptoms that pre-dated the pregnancy. Experiences of stressful life events and mood disorders have been associated with sexual behaviors that place women at risk for unplanned pregnancies (Harris and Campbell 1999; Ethier et al. 2006).

No significant change over time was observed for maternal perceptions of stress, symptom distress, depressive symptoms or 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 may represent the psychosocial milieu of their lives regardless of additional challenges that living with HIV infection poses. Levels of stress and depressive symptoms may remain relatively constant for many women because they reflect the environment they have dealt with for years (Beeghly et al. 2003).

There are a number of limitations in this study that should be acknowledged. The generalizability of these results to all HIV infected mothers is limited by the small sample size and the demographics of participants. Our sample was primarily drawn from two sites on the west coast of the United States (San Francisco and Alameda Counties in California) where the majority of women are recipients of Medicaid. Estimates from the Surveys of Childbearing Women (San Francisco HIV Epidemiology Report 1998), as well as a population-based survey of women in low income San Francisco neighborhoods (Ruiz et al. 2000), suggest a prevalence of 0.2% - 0.3% (95% CI, 0.1%-0.4%). During the data collection period there were 8,500 births per year in San Francisco. Of the estimated 31– 46 HIV-infected pregnant women living in the geographic region where the study was conducted, some were unaware of their infection during pregnancy and others elected for pregnancy termination. Therefore, an estimated 25 to 35 women were eligible to participate in the study. Consequently, we enrolled a substantial proportion of eligible women.

In this study, 40% of the women were African American while 64% of adolescents and women living with HIV/ AIDS identify as African American in nationally collected data (CDC 2006). While national surveillance data from anonymous reporting indicates that 72% of women identify heterosexual contact as the mode of HIV acquisition (CDC 2006), it was 90% in our sample. All participants were engaged in prenatal and HIV-specialized care, 90% were aware of their HIV status prior to pregnancy and all were identified as being HIV-positive at least several months prior to delivery. In addition, all of the women reported that they were the primary caretakers for their infants. Women who differ from these characteristics may experience different patterns of stress, symptom distress, depressive symptoms, 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 infant's health if they are unable to obtain information about their infants' test results. The HIV medical expertise and community resources available to the women in the San Francisco Bay Area may have also influenced the results. HIV-infected pregnant women living in other communities where resources are not as extensive may experience more stress and depression, as well as different patterns of resolution of uncertainty about their infants' HIV infection status. Finally, one of the measures, the PPUS-D, has not been validated for use during pregnancy but was considered the most appropriate for measuring maternal perceptions of uncertainty about infant HIV status for this study.

### Conclusion

Findings indicate that HIV-infected women experience decreasing levels of uncertainty about the infection status of their infants as each HIV viral test result is revealed. In addition, their perceptions about conflict within their social networks decline as they become more confident that their infants are not infected. While perceptions of stress, symptom distress, depressive symptoms and social support did not change over time, the pattern of maternal resolution of uncertainty was affected by the presence of depressive symptoms and whether or not the pregnancy was planned. In addition, those who reported more social support had significantly less uncertainty throughout the testing period.

Results from 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 psychological symptoms. Finally, despite the low probability of infants being infected, the high prevalence of chronic depressive symptoms in this group of mothers underscores the importance of ongoing clinical assessments and the initiation of interventions to treat depression prior to, and after, HIV-infected women give birth. While this population of women may be hesitant to use pharmacologic interventions for their depressed mood because of side effects or possible interactions with other medications (e.g., HAART), clinicians need to reinforce the importance of appropriate treatment for depression so that maternal health, maternal-infant interactions and the infant's development can be optimized. There is also a need for further research investigating pharmacologic and non-pharmacologic interventions for treating depression in this population.

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