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The National Abandoned Infants Assistance Resource Center's mission is to enhance the quality of social and health services delivered to children who are abandoned or at risk of abandonment due to the presence of drugs and/or HIV in the family by providing training, information, support, and resources to service providers who assist these children and their families. The Resource Center is located at the University of California at Berkeley, and is a service of the Children's Bureau.

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Having entered the third decade of the epidemic, HIV is considered worldwide to be a disease of women, children, and families. In fact, the first National Women and Girls HIV/AIDS Awareness Day was announced in 2006 to recognize the disease’s increasing impact on women in the United States. Although women’s overall rate of diagnosis decreased from 2001 to 2004, rates have remained disproportionately high for Hispanics and especially African-Americans (McDavid, Li, & Lee, 2006)—5 and 21 times higher, respectively, than the rate for White women. African American and Hispanic women together account for 83% of AIDS diagnoses reported in 2003 (Centers for Disease Control and Prevention [CDC], 2003; Spraggins, 2000), although they represent about 25% of all U.S. women.

The development of highly active antiretroviral treatments in the 1990s has prolonged survival for HIV-infected women, extending their time for bearing and raising children. The number of births to all HIV-infected women was estimated to be between 8,650 and 8,900 in 2006, approximately 30% higher than that reported in 2002 (Whitmore, Zhang, & Taylor, 2009).

Research has shown that chronic illness is a major stressor for the entire family, and illness severity has been linked to higher levels of psychological distress in chronically ill adults and their children. Anyone diagnosed with HIV/AIDS faces the physical and psychological challenges of living with a chronic disease, along with the repercussions of disease-associated stigma. Research has shown that chronic illness is a major stressor for the entire family, and illness severity has been linked to higher levels of psychological distress in chronically ill adults and their children. Mothers living with HIV (MLH) must also meet childrearing tasks and buffer their family from the negative impact of their illness. MLH report that their greatest source of stress is combining the maternal role with the psychological and medical demands of coping with a chronic, life-threatening condition.

In spite of the growing numbers and pressing needs of this population, we still have limited knowledge about the mothers themselves, the impact of illness on parenting and on their children, and how to provide effective support services for these families. This article addresses the impact of maternal HIV/AIDS in the United States on the mothers themselves, their children, and the parent-child relationship. Findings are based on a 15-year study whose research model focused on child outcomes; however, a great deal was also learned about the mothers themselves.


THE PACT STUDY AND SAMPLE

PACT I, the original observational study upon which the model is based, began in 1997 when the children were 6 – 11 years of age. One hundred and thirty-five families were recruited and followed every six months for 36...
months. Mothers and their children were interviewed separately at each follow-up. In 2002, PACT II (Parents and Adolescents Coping Together), a continuation of PACT I, allowed the research team to keep following these families every six months as the children transitioned to early and middle adolescence. The final study, PACT III, began in 2008 and will end in 2013. It is designed to continue studying the families as the children transition from early/middle adolescence to late adolescence/early adulthood.

At the PACT I baseline, the mean age of the mothers was 34.7 years. The sample's racial/ethnic composition was 39% African American, 26% Latina, 21% White, and 15% mixed or other race. Almost half (48%) had not completed high school; approximately one-third (31%) were high school graduates, and the remainder had completed some college or technical school or had an undergraduate degree. Only 23% of the mothers were married; the rest were single mothers. The majority were living in poverty in urban areas throughout Los Angeles, San Bernardino, and Riverside counties.

**OVERVIEW OF THE PACT MODEL**

Only recently have the effects of maternal HIV on children and adolescents begun to be examined. Figure 1 depicts the general model of these effects developed by Murphy within our ongoing PACT studies (e.g., Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002; Murphy, Marelich, & Amaro, 2009). This review discusses a number of maternal background and intermediate factors affecting long-term child outcomes: mental health status, behavioral adjustment, and social adjustment. In presenting how maternal factors interact to affect children, a window is also opened to explore the challenges faced by the mothers themselves. Child factors shown in Figure 1 are not covered.

---

**Figure 1: PACT Theoretical Model**

- **Child Background**
  - Age
  - Gender
  - Ethnicity
  - Cognitive Ability
  - Health & HIV/AIDS Knowledge

- **Maternal/Family Background**
  - Ethnicity
  - Socioeconomic Status
  - Health Status
  - Mental Health

- **Child Intermediate Outcomes**
  - Coping Skills
  - Self-concept
  - Gender Role & Identity Formation
  - Social Relationship Norms & Interpersonal Support (Parental, Peer, Partners, Stable Adult Figure(s))
  - Autonomy
  - Knowledge of Parental HIV & Associated Perceived Stigma

- **Maternal Intermediate Factors**
  - Life Events & Parenting Stressors
  - Coping & Parenting Skills
  - Disclosure of HIV Status
  - Support Network
    - Size, Norms & Quality

- **Child Outcomes**
  - Mental Health
  - Behavioral Adjustment
    - Internalizing & Externalizing Behaviors
  - School Connectedness
  - Delinquency
  - Alcohol & Substance Abuse
  - Sexual Risk Behavior
  - Social Adjustment (Parental, Peers, Adults)
Among HIV-positive individuals, low SES is associated with poorer quality of life. HIV is disproportionately high among inner-city, poor women, most of whom fall in the lowest socioeconomic class and face many life challenges, including significant barriers to health care. In metropolitan areas, which often have high crime rates, the majority of mothers with HIV/AIDS is on public assistance and also exposed to high levels of violence, both of which put them at risk for emotional distress. Finally, an estimated one in five new HIV diagnoses among women is related to injection drug use (CDC, 2004). Many more women are indirectly affected by substance abuse through an association with someone who uses, adding to the SES burden. SES may indirectly impact child and adolescent outcomes, through its effect on maternal stress and coping, as well as on perceived stigma related to poverty.

HEALTH STATUS

The health of the PACT mothers has been variable over time, partly due to their erratic compliance with medication protocols. Mothers have had very poor adherence rates (Murphy, Greenwell, & Hoffman, 2002), ranging from 43% (pill count assessment) to 56% (self-report of three-day adherence to dose). Factors associated with non-adherence include: alcohol use, perceived stress, having a partner, age of youngest child, a lack of confidence in their ability to maintain the treatment regimen, and low expectations of positive health outcomes from following the treatment regimen.

As illness progresses, mothers with HIV find it increasingly difficult to maintain tasks of daily living and parenting, which then disrupts relationships with their children. For example, PACT mothers experiencing physical decline have been less likely to maintain family routines or to monitor their children’s activities, resulting in poorer child outcomes. Maternal illness has also been found to be a risk factor for resiliency (Murphy & Marelich, 2008). Children identified as resilient have lower levels of depressive symptoms and report higher levels of satisfaction with their ability to cope effectively with difficult situations. However, as maternal viral load increased in the study, resiliency among the children decreased.

When mothers remain healthy, their children exhibit fewer depressive symptoms (Murphy, Marelich, & Hoffman, 2002). Moreover, a higher level of maternal physical functioning is related to better child self-concept, which in turn positively affects child depression levels. Stability in maternal health also appears to be associated with a more rapid improvement in children’s mental health indicators over time.

Maternal/Family Background Factors

ETHNICITY

Ethnicity has a powerful impact on family responses to HIV. It can shape perceptions of illness, health care use, and attitudes toward providers (Chavez, Hubbell, McMullin, Martinez, & Mishra, 1999). It can also influence how individuals experience pain, label symptoms, and communicate about illness. Among HIV-positive adults, ethnicity has a bearing on treatment status. Ethnic minorities, primarily African Americans, are more likely to be untreated (Kalichman, Graham, Luke, & Austin, 2002). Rates of disclosure to family and friends are significantly lower for African Americans than for Whites (Petrik, Doyle, Smith, Skinner, & Hedge, 2001). Moreover, HIV-positive African American women report significantly more depression than Caucasian men or women (Lichtenstein, Laska, & Clair, 2002). In a study of Whites, African Americans, and Hispanics, receipt of highly active antiretroviral therapy was lowest for Hispanic women, and mild depression was more prevalent (Turner & Fleishman, 2006). Thus, ethnicity may affect child outcomes through its impact on mothers’ access to care and support and consequent maternal health.

SOCIOECONOMIC STATUS (SES)

The effect of socioeconomic status on morbidity and mortality is well known: Health improves as socioeconomic level increases, and this holds true across different ethnic and racial groups. The challenges of living in low socioeconomic environments may reduce an individual’s capacity to manage stress, thus increasing vulnerability to illness.

In metropolitan areas, which often have high crime rates, the majority of mothers with HIV/AIDS is on public assistance and also exposed to high levels of violence, both of which put them at risk for emotional distress.
PACT studies have found that White mothers reported more stressful events in their lives than Latina mothers, and Latinas reported fewer events than African-American mothers; however, almost all mothers reported some stressful life events. These findings are similar to reports by other investigators (Brackis-Cott et al., 2007; Catz, Gore-Felton, & McClure, 2002; Jenkins & Coons, 1996). Further research is needed to explain these ethnic differences.

**PARENTAL COPING AND PARENTING SKILLS**

Coping—the ability to deal adequately with responsibilities and challenges—is often associated with mental health. People with HIV/AIDS who use ineffective coping strategies tend to have lower levels of energy and social functioning, and greater depression (Vosvick et al., 2003), as well as significantly poorer quality of life. Parental coping is obviously critical for child health and well-being. A mother’s poor coping has been related to child adjustment problems. Moreover, maladaptive coping and the number of children a woman has have been associated with poor adherence to medical treatment—which in turn can influence maternal health.

Parenting skills may protect children at risk. Some studies have found that parenting skills, such as implementing and maintaining family routines and monitoring children’s activities, can be protective factors for early and middle adolescents. In PACT families with more frequent family routines, adolescents had lower rates of aggressive behavior, anxiety/worry, depressive symptoms, conduct disorder behaviors, and binge drinking, and exhibited improved self-concept over time (Murphy, Marelich, Herbeck, & Payne, in press). Adolescents in PACT families with higher levels of parental monitoring showed significant declines in anxiety and depressive symptoms, conduct disorder behaviors, and binge drinking, along with improvements in self-concept.

As mentioned above, PACT studies show that as illness progresses, mothers are less able to maintain parenting activities, with an array of negative effects on their children. Additionally, Dorsey et al. (1999) found a linear increase in children’s behavior problems and emotional distress as their mothers progressed through stages of HIV infection and then AIDS.
on mental health indicators at the assessment following disclosure, including lower depression scores and a trend towards lower anxiety scores. Although the majority of children seemed to adjust well over time, a small number evidenced sustained problems following maternal disclosure, indicating a need for referral to therapy.

As Baumgartner (2007) has noted, people incorporate their HIV/AIDS diagnosis into their identity over time, and disclosure is a component interwoven throughout the process. Further investigation is needed to understand how disclosure to children, and children’s developmental process, may influence the ways in which mothers incorporate illness into their identity.

SOCIAL SUPPORT

A large body of literature exists on the importance of social support for the physical health of HIV-positive individuals. Having a larger social support network has been directly associated with better mental health and overall quality of life among HIV-positive women (Gielen, McDonnell, Wu, O’Campo, & Faden, 2001). Social support among HIV-infected mothers is typically associated with less emotional distress. Additionally, behavior change, such as medication adherence and improved parenting skills, can only be sustained if there is support for the changes over time.

Unfortunately, HIV-positive women—especially those who do not disclose or disclose to very few people—find it difficult to build a social support network. In some studies, HIV-infected mothers and children have been found to report less social support compared to non-HIV-affected families. This may be due in part to isolation imposed by illness itself, general reluctance to ask for help when ill, or fear due to perceived stigma related to HIV. In addition, for some period of time, HIV/AIDS services focused primarily on the needs of gay men, intensifying HIV-positive women’s feelings of isolation (Andrews, Williams, & Neil, 1993). Determining the relationship of HIV to social support systems remains complex, while the need for support remains great.

DISCLOSURE OF HIV STATUS

Whether, when, and how to divulge the reality of HIV to their children is a profound challenge faced by infected mothers. Mothers find telling their children to be the most challenging disclosure, and anticipating these difficulties is frequently translated into indecision and putting off disclosure (Tompkins, Henker, Whalen, Axelrod, & Comer, 1999). Mothers in the PACT studies who disclosed to children reported having a stronger social support network, specifically people with whom they could share personal and private feelings. Thus, providing mothers with supportive circumstances in which they can practice disclosure may benefit mothers and children alike.

Maternal disclosure of HIV can affect child adjustment and the mother-child relationship. There are potential risks and benefits associated with disclosure for both mothers and children. Armistead and colleagues (2001) found that mothers perceived children as demonstrating a variety of reactions to disclosure, with approximately half reacting in a positive manner and about 40% reacting with a negative affect such as anger, fear, or rejection. Positive experiences of disclosure have been characterized by open, honest communication and closer relationships between mothers and children.

Mothers find telling their children to be the most challenging disclosure, and anticipating these difficulties is frequently translated into indecision and putting off disclosure.

Appropriate disclosure may enable children to deal positively with maternal illness. Conversely, children’s confusion and anxiety about their mother’s health may be likely if such discussions do not occur, since nondisclosure is no guarantee of positive child outcomes. It has been suggested that distress exhibited by younger children when their mothers have not disclosed may be due to the guilt youngsters feel for a disordered family environment whose source they cannot identify (Weiner & Septimus, 1990).

PACT research (Murphy, Austin, & Greenwell, 2006; Murphy, Marelich, & Hoffman, 2002) indicates that children aware of their mother’s HIV status are, for the most part, doing better than those who are uninformed. The majority of children showed significant improvement...
PERCEIVED HIV-RELATED STIGMA

HIV-related stigma is associated with psychological distress and can interfere with coping, adjustment, and management of disease. Mothers with HIV worry about fear, anger, blame, and stigmatization from family and friends (e.g., being perceived as an irresponsible or “bad” mother), as well as from their children. They also fear further disclosure to others through their children.

PACT mothers who reported high levels of HIV-related stigma had impaired physical, psychological, and social functioning. They also reported higher levels of depression, health-related anxiety, more alcohol use, and poorer medical outcomes such as fatigue, pain, and physical health (Murphy et al., 2006). This is consistent with previous work that indicates that stigma is predictive of limited daily functioning. Moreover, among children aware of their mothers’ HIV status, those who perceived high levels of stigma were more likely to engage in delinquent behaviors, compared with children reporting low HIV-related stigma.

The relationship between social support, disclosure, and stigma illustrates the interplay among factors represented in the PACT model. For example, women with good social support are more likely to disclose their HIV status to their children. Disclosure can facilitate the mothers’ ability to utilize existing social support and identify and gain access to additional social resources. However, fear of negative outcomes of disclosure, resulting from HIV-related stigma, can inhibit such utilization.

Summary

Being a mother living with HIV is somewhat of a paradox. Through caring for a child, mothers are caught up in life. Having a child may decrease feelings of isolation and stigma associated with the disease and force engagement with others, resulting in what Andrews et al. (1993) termed “a strong attachment to the world.” On the other hand, children can add stress to already stressful lives. Mothers must deal with their physical health, the limitations illness may impose on parenting, as well as the guilt they may impose on themselves for the additional struggles their children endure.

Given the severe challenges mothers with HIV/AIDS face and the relatively poor outcomes of their children, interventions are sorely needed for this population. The studies reviewed here shed light on the factors that services need to target. For example, we know that many mothers need assistance in how to disclose their status to their young children and adolescents and that following disclosure some children will need short-term support. We also know that children are aware of the stigma related to HIV/AIDS and are concerned about their parents and themselves being stigmatized. They may very well need assistance in coping with their feelings and the reactions of others. Additionally, we know that these mothers are dealing daily with physical limitations, perceived stigma, and psychological distress—particularly depression. However, we know very little about how to provide mental health and parenting interventions effectively. For example, is it best to work on improving parental intermediate factors affecting child outcomes, or would it be better to adopt a multi-pronged approach that also targets parental background factors affecting the intermediate factors, while simultaneously attempting to improve child and family outcomes directly? As can be seen from this review, research has only progressed to the stage of identifying factors associated with child outcomes. Investigators and clinicians need to use this information to identify successful methods of improving the lives of these families, for the sake of the mothers, the parent-child relationship, and the well-being of the children.

Although few tested intervention programs exist for women living with HIV, and even fewer for infected mothers, there have been several promising possibilities. Some psychosocial interventions have been shown to be effective in reducing HIV risk behaviors, as well as improving the quality of life for infected individuals. For example, the SMART/EST Womens’ Project (Ironson et al., 2005; Jones et al., 2007) has shown improvements in HIV-positive women’s cognitive behavioral skills, self-efficacy, adherence to HIV-medications, and emotion-focused coping. Perhaps what mothers living with HIV need most urgently are parenting interventions. As the AIDS epidemic continues, growing numbers of children are living with an infected mother. These women face incredible challenges raising their children, and the children are at risk for poor outcomes.

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To our surprise, significant racial differences did not materialize in the analysis and will therefore not be addressed here. However, maternal ideologies, as expected, critically affected how the women experienced both their HIV status and their mothering.

The Study

In-depth interviews were conducted in 2007 with a sample of 17 HIV-positive mothers, 24 to 58 years old, and of equal mix of White and African American. The mothers averaged two children each, with four of them parenting one or two non-biological children. Most lived in the suburbs of a Midwestern city and all but three were receiving public assistance. They had been HIV-positive between 4 and 19 years; four had AIDS. Seven had male partners in the home; the others were single, divorced, or widowed. Six had a history of substance abuse.

One private in-depth interview, averaging two hours, was conducted with each of the mothers. Data were analyzed using standard techniques of qualitative thematic analysis (Smith & Osborn, 2003). The emerging themes illustrate how these mothers see their lives strongly characterized by the dual challenges they face in addressing their illness while raising children.

How HIV Affects Mothering Experiences

Managing HIV required a good deal of the mothers’ time, attention, and energy, often undermining their ability to always put the care and protection of their children first. The mothers used numerous strategies to cope with their illness while trying to meet the expectations of mothering. Some made a conscious effort to get rest, especially when...
their children were at school: “I always make it a point to sleep during the day.” Mothers also timed medication intake so that acute side effects would occur after children’s bedtime. Some relied on friends, family, and/or children for help: “If I’m sick [my daughter] takes that baby and she’ll feed it lunch. She’ll change her diaper. However, relying on children was double-edged.

While some mothers noted that their children were exceptionally mature and responsible for their age, it was often associated with guilt. They agonized over feeling they were constantly putting their children on hold or expecting too much of them. One mother was distressed about allowing her son to play video games for hours so that she could rest after taxing workdays. Others bemoaned their inability to perform activities that healthy mothers take for granted: “I see moms out here taking their kids to the park and being able to do more with ’em. That affects me a lot because my days are really limited.”

In spite of living longer and healthier lives (Centers for Disease Control and Prevention, 1997), uncertainty about the possibility of becoming seriously ill and dying still haunted them: “I know eventually there’s gonna come a time where I am gonna get sick and I don’t know what’s gonna happen to her.” This fear pushed mothers to concentrate on helping children, especially their eldest child, attain independence so they could assume responsibility for younger siblings: “Then if something happens to me, hopefully [my oldest daughter] would take care of my other daughter.”

The same concerns focused many mothers on the present. Their interviews resonated with the urgent need to do as much as possible with their children now: “I put everything into today ‘cause, you know, I never know when it’s gonna come a time when I’m not gonna be able to do it.”

In some limited ways, having an HIV diagnosis can enhance the mothering role. For example, experiences with HIV expanded the mothers’ motivation and follow-through to thoroughly educate their children about safe sex and drug use. In doing so, the mothers clearly articulated the maternal norm of protecting their children from harm. Nearly all of them had frank and open discussions with their children: “I have told them, it’s not all about prevent-ing pregnancy. There’s diseases out there.”

Many studies show how challenging disclosure is for mothers because they fear stigmatizing their children (Faithfull, 1997; D. A. Murphy, Roberts, & Hoffman, 2003; Ostrom, Serovich, Lim, & Mason, 2006; Tompkins, Henker, Whalen, Axelrod, & Comer, 1999). Most of the mothers in this sample, however, felt strongly about disclosing to their children as a way to both protect and educate them. “By them growing up knowing that I was HIV, I felt like that helped to keep them safe at the same time.” Others used disclosure to their children as a teachable moment about the pitfalls of drug use: “When I’m telling you don’t do it [drugs], this is why, because Mommy knows.”

The few mothers who didn’t disclose also regarded their decision as a way to protect their children. Some feared that disclosure would harm their children by leaving a negative image of their mothers: “I don’t want to make a little sad person: my mommy was sick. I had to watch my mommy die.” Presenting an idealized image, which often accompanied nondisclosure, was also a way to mitigate or combat stigma, again with the desire to provide protection: “I’m gonna depict a good image. All that [school] is about the kids, ‘cause it’s their turn. And so I want to leave them with a good memory.”

Most striking is how little impact HIV had on the mothers’ deeply held maternal desires. Despite illness, all of the women embraced the maternal role and felt that all women should have children, regardless of their HIV status. “Everyone’s supposed to have children.” And, “I believe every woman should [have] at least one [child].” Several women shared that, in terms of their identity, being a mother eclipsed being HIV-positive. It is here that the cultural expectation for women to desire and have children was particularly salient. Raising healthy children and managing solid families allowed these women to assert to society that HIV had not changed them as women.

How Motherhood Affects Living with HIV

Just as living with HIV exerts a profound impact on women’s experiences as mothers, the experience of being a mother, as well as maternal ideologies, exerts a corresponding impact on the experience of living with HIV. These influences are mostly positive. For instance, the women repeatedly underscored their relationship to the normative experience of motherhood, asserting that they were “just like any other mom.” “I really don’t look at it as being a mom being HIV-positive. I’m a mom first.” Their status as mothers helped diminish the illness identity and normalize their sense of self.

Being a mother also made it easier for these women to keep HIV from overwhelming their lives: “[Taking care of my daughter] made me put my condition in the back of my head, you know. That’s not even important now. She’s important. My condition is second.” Adopting a perspective that “it could be worse” while concentrating on the positive aspects of their lives, including their children, seemed to diminish the overwhelming focus on HIV. “I always remind myself that I need to be thankful. Because I have two children that are negative, beautiful, healthy children.”
Having children also kept many from sinking into overwhelming depression. One mom noted, “I believe if I had [HIV] and I didn’t have no kids, I would’ve probably killed myself.” Another mother said, “If it hadn’t been for the fact that I was bringing a child into this world, I think I probably would have been in such a depression state [as to be suicidal].”

Having children and putting them first, also served as a primary motivator for self-care, even as it made it harder. For example: “You can’t be selfish anymore. You gotta take care of yourself, because you’ve brought this little boy into your lives, and you have a responsibility to take care of him.” “She’s the reason why I feel like I want to fight this thing and I wanna live.” “I’m not taking my medicines for me; I’m taking it for them.”

On the other hand, managing illness while trying to put children first often took its toll: “Being a busy mom and working and taking care of [everything], there were some times that I was missing dosages and stuff like that.” “Except, having a child now, [it] is hard to say whether it’s work or being a mom or the combination of the added responsibility—I don’t take care of myself as well.”

Some mothers experienced grief in not being able to actualize their motherhood expectations, like having a natural delivery or breastfeeding. Many mothers compared themselves to the idealized image, especially when they failed to live up to it. Leah, for example, expressed profound guilt for the drug addiction and incarceration that had kept her from being a “good mother in the past.” Of her wayward years, she concluded: “I was really selfish then. I didn’t consider my children … I was a terrible mother for about three years because I was selfish. And the abortion, that was selfish. That weighs on me. That makes me feel like a terrible mother.”

## Conclusion

These preliminary findings suggest that mothering with HIV involves negotiating cultural ideologies of proper motherhood with the difficulties of actualizing them, made more difficult by their illness. The women all expressed strong maternal desires, shared a “duty to care,” and were self-sacrificing. Even though the illness sometimes impaired their maternal role performance and sense of adequacy, the mothers struggled to find coping strategies that would help them manage the unique constraints of being HIV-positive while living up to their expectations of themselves as good mothers.

But, while the illness undermined mothering, the experience of being a mother was generally beneficial, at times promoting the will to live, and providing them with a positive, self-affirming identity in the face of a debilitating and stigmatized illness. While much remains to be learned about the lives of mothers living with HIV, these findings suggest that service providers might reinforce the positive role that mothering can play in these women’s lives as a way to help them cope with HIV. At the same time, providers should be sensitive to some of the challenges that mothers with HIV face in trying to live up to idealized standards of motherhood, such as neglecting their own health and feeling guilty for contracting their illness.

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Sources of Distress for Southern African American Mothers with HIV

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African American females are disproportionately affected by HIV infection compared to those of other races. In 2008, the Centers for Disease Control and Prevention (CDC) reported that the HIV incidence rate for Black women was nearly 15 times as high as that of White women (55.7 per 100,000 compared to 3.8 per 100,000) and nearly four times as high as that of Hispanic/Latino women. Most African American women diagnosed with HIV are mothers who are poor (Shaw & Bradbeer, 2000; Smith et al., 2000). As such, they cope with many stressful issues related to raising children in poverty. This is especially true for African American mothers in the South, which has high rates of poverty and unemployment and a lack of resources (Heckman, 2006; Stewart, Cianfrini, & Walker, 2005). Living with an HIV diagnosis increases their burden.

This article will describe the multiple sources of distress experienced by African American mothers with HIV living in the South. Findings are based on a four-year longitudinal study, the framework of which is intersectionality as described by Berger (2004). Intersectionality refers to the idea that minority women are already socially disadvantaged, making them even more vulnerable when also faced with an HIV diagnosis, which causes further oppression and distress (Gilbert, 2003). Our study examines two main sources of distress: those based on the general life challenges of rearing children in poverty and those related to the HIV diagnosis.

Background

HIV-positive women experience high levels of psychological distress, including anxiety, depression, and lowered mood states (Catz, Gore-Felton, & McClure, 2002; Mellins, Ehrhardt, Rapkin, & Havens, 2000; Miles, Holditch-Davis, Pedersen, Eron, & Swartz, 2007). Mothers of sero-positive infants worry about the health status of their infants (D’Auria, Christian, & Miles, 2006; Shannon, 2007). Living with HIV raises anxiety about health, particularly disease complications, physical symptoms such as fatigue, and mortality (Miles, Gillespie, & Holditch-Davis, 2001). Mothers, in particular, report high levels of concern about dying and about future guardianship of their children (D’Auria et al., 2006; Mellins et al., 2000). In addition, they worry about access to medical care and the cost of treatment and drugs. A major ongoing source of distress is the fear of being stigmatized and related issues of disclosure (Black & Miles, 2002; Sandelowski, Lamb, & Barroso, 2004; Whetten-Goldstein & Nguyen, 2002).

Apart from their illness, low-income African American mothers are exposed to multiple stressors in their daily lives (Ghate & Hazel, 2002; Simoni & Cooperman, 2000), the major ones being acute and chronic financial strain, lack of adequate employment, inadequate and unsafe housing, physical and sexual abuse, family conflicts, and exposure to violence (Gilbert, 2003; Leslie, Stein, & Rotheram-Borus, 2002; Schrimshaw, 2003). For poor, unsupported single mothers, childcare responsibilities are daunting (Ghate & Hazel, 2002). The intersection of stressors associated with HIV, such as secrecy and concern about stigma, with those of mothering in poverty can lead to profound loneliness (Black & Miles, 2002).

Focusing on the social context of HIV for these mothers and providing appropriate supportive interventions is critical considering the magnitude of their own health and human needs, as well as the potential impact on their children and families.

Methods

Data for this qualitative descriptive study come from a larger longitudinal study (1993 to 1997) that investigated the parental caregiving of infants seropositive for HIV (D’Auria et al., 2006; Holditch-Davis et al., 2001; Miles et al., 2001). Recruited from two Southeastern university hospitals, eighty-seven primary caregivers (biological mothers, kin,
and foster mothers) and their infants, were enrolled at around three months of age and followed longitudinally until two years old.

Participants for this article were 51 African American biological mothers with HIV. Their mean age was 31 years, 58% and had a high school or higher level of education. Only 24% worked and the mean annual household income was $14,086. Nearly all (91%) were on Medicaid. Over half (56%) came from rural areas.

Data were collected from tape-recorded semi-structured interviews conducted in the home or at a clinic visit. The interviews focused on the women themselves and their maternal role (perceptions of their child, concerns about parenting, and worry about their child). Mothers also were asked about specific stressors in their lives and about any other worries, concerns, or fears. The data were analyzed using methods of content analysis (Marshall & Rossman, 2006). Specific statements related to concerns or stress were grouped according to the source of distress and then clustered conceptually into themes. The sources of distress largely revolved around the challenges of raising children in poverty and those of living with HIV.

Living and Parenting in Poverty

Poverty issues grouped into three main areas: the struggle for life’s basic necessities, caregiving stress, and interpersonal stress and conflict.

Basic Necessities of Life

About half of the participants mentioned financial issues as one of their biggest stressors, including insufficient money for bills, rent, food, milk, and pampers. One mother said “But dis man made stuff like light bill, food and stuff lik dis... das so high. Das wats worryn’me, das what I call the man made stuff.” Few mothers received support from the fathers and many could not work because they were on disability. Mothers living in rural areas without public transportation or a car found it difficult to get a job, get to work, or even accomplish simple tasks like grocery shopping. Inadequate housing was another basic necessity of great concern. Many mothers lived with extended family in crowded housing situations or unsafe public housing where they worried about safety. A number of mothers moved multiple times during the four-year study period in order to reduce costs or find better housing in safe neighborhoods.

Living in the Context of HIV

Mothers’ concerns related to having HIV also clustered in three areas: the health of the infants, their own illness and mortality, and emotional responses to having the disease.

Health of Infants

A major source of distress for the mothers in this study was concern about whether or not their baby had HIV. Repeated testing was done, sometimes for months, creating a time of great uncertainty and anxiety. Mothers whose infants were diagnosed with HIV worried about their health status and care. This anxious focus on the children often precluded caring for their own health.
**ILLNESS-RELATED DISTRESS**

Mothers did report overwhelming worry and distress related to living with a serious disease, including the frequency of clinic visits, transportation to clinic, and the costs of medications. These issues were particularly stressful for those whose illness had progressed. Mothers with more advanced disease were also upset by chronic fatigue and the side-effects of HIV medications, often making it difficult to keep up with childcare and household responsibilities.

Many mothers expressed worries about their future health and fears about dying. As mothers, however, they often placed their concerns in the context of how their illness and possible death would affect their children. “What will happen to my child if I die or become too ill to care for them?”

**EMOTIONAL RESPONSES**

Mothers reported feeling guilt, anger, and regret for having been infected with HIV, blaming themselves for their own past risky behaviors or their naiveté about infected partners. Shame and concern about being stigmatized was a major source of distress. The mothers constantly worried about disclosure, about how others would think of them and treat them if they knew. Some had already experienced stigma as a result of having HIV and were hesitant to disclose to more people. Secrecy, subsequent limited support, and experiences with stigma all added to their loneliness and emotional distress.

Curiously, when asked directly about stressors, some women appeared to have difficulty answering. They would say “nothing” or “not much” or “couldn’t say,” thus denying any stress. This was in sharp contrast to their comments in other parts of the interview or in field notes recorded by the staff. Sometimes these replies were qualified with comments like “try not to think about it,” or “I don’t stress myself out.”

**Discussion and Implications for Practice**

Findings support the intersectionality model as a way of understanding the distress of African American mothers with HIV. Their distress was intricately woven through both their social position as minorities living in poverty and their struggle in living with a stigmatized illness. The major implication for practice is that professionals working with these mothers must view their needs in the context of their whole, complex lives. Providing interventions aimed at reducing their distress is urgent because numerous studies have found that stress increases the morbidity and mortality of individuals with HIV (Ickovics et al., 2001; Leserman, 2003; Stewart et al., 2005). Impairment of health, disability, and death has major implications for their capacity as parents and the needs of their children.

It is no surprise that financial assistance is critical. Helping mothers secure training, adequate employment, and child care can both reduce distress and support a positive self-image. Finding safe and adequate housing cannot be emphasized enough as another way to reduce distress and improve the lives of mothers and their families (Miles, Holditch-Davis, Pederson, Eron, & Schwartz, 2007; Stewart et al., 2005). These positive steps and the provision of hope can help mothers focus more on their own health care needs and improve their parenting.

The mothers’ concerns for the well-being of their infants, particularly regarding their HIV status, strongly underscore the centrality of children and the mothering role for these women. Seeing themselves as good mothers was an integral part of their self concept (D’Auria et al., 2006). Thus, interventions that help them improve their parenting skills and that positively reinforce their maternal role are important. The mothers also need help in finding adequate childcare to support their employment, and respite care to reduce isolation and loneliness. Since these mothers were concerned about how their illness might affect their ability to continue parenting, other services should help them improve self-care activities (Miles et al., 2003), such as seeking and following through with HIV and preventive health care, good nutrition and exercise, early treatment of infections, and learning how to manage HIV-related fatigue. Many mothers need assistance in obtaining treatment for drug, alcohol, and cigarette abuse. Such self-care efforts will enhance maternal well-being, which is especially important now that HIV can be considered a chronic disease and life can be prolonged for many years with proper care.

Counseling strategies to help mothers share their feelings and concerns about having HIV and other life issues can reduce distress and depression. Counseling is also critical in helping them deal with ongoing anxieties about disclosure and stigma. Unfortunately, these concerns are not abating, particularly in rural areas where access to mental health counseling is very limited (Reif, Whetten, Ostermann, & Raper, 2006; Whetten-Goldstein & Nguyen, 2002).

The absence of responses of some mothers regarding stress in their lives, despite evidence to the contrary, may reflect a resigned acceptance to pervasive and chronic life stress, as well as a need to appear strong, a characteristic of African American women described by some authors (Shambley-Ebron & Boyle, 2006; Williams, 2008). This
need to appear strong may reflect the depth of their pain as minority women who have faced oppression and discrimination, compounded by the stigma of HIV. Williams (2008) has described Black pain as unique and profound, resulting from experiences in facing oppression and discrimination that is so deep and distressing as to be hidden and silent. Professionals working with mothers need to be aware of these phenomena and assess their needs with sensitivity and care.

This article has focused on emotional distress in African American mothers with HIV. We did not address their cultural and personal strengths, which include the centrality of parenting, skills to manage complex lives with scarce resources, women kin-centered networks, and spirituality (Gray & Cason, 2002; Polzer & Miles, 2008; Shambley-Ebron & Boyle, 2006; Serovich, Kimberly, Mosack, & Lewis, 2001; Simoni & Cooperman, 2000). Caring professionals will need to build on these women's strengths while also helping to reduce their many sources of distress.

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Disclosing an HIV-positive status to children and family members is usually overwhelming for mothers. Disclosure to children and future caregivers is also a topic of critical importance in the field of voluntary permanency planning for families affected by HIV/AIDS. From both legal and psychosocial perspectives, disclosure impacts a mother’s ability to make a legal future care and custody or “backup” plan for her children.

Since the Abandoned Infants Assistance (AIA) initiative began over two decades ago, permanency planning has been recognized as an integral component in preventing child abandonment and preserving families. The AIA initiative remains instrumental in developing permanency planning services and policies for families affected by HIV, as well as in creating and testing new legal permanency options. This article will discuss the complex circumstances that can present obstacles to HIV-disclosure. It will also show how an interdisciplinary model can support families through the permanency planning process.

Helping them confront and cope with their diagnosis increases the chances that families will achieve stability both during maternal illness and after death.

Families’ and Children’s AIDS Network (FCAN) Family Options Project

FCAN’s AIA-funded permanency planning project, Family Options, has led the development of new programs and policies promoting permanency planning and family support for HIV-affected families. In Illinois, these new legal options include standby guardianship, standby adoption, short-term guardianship, and a host of other guardianship and adoption reforms.

Based in Chicago, Family Options offers comprehensive, interdisciplinary legal and social work services to families when at least one parent is HIV-positive in order to help them make future care and custody choices for their children. Since its inception in 1996, Family Options has served over 500 caregivers with more than 1,000 children. Most of these caregivers are mothers. In this article, “mothers” refers to HIV-positive parents, and “caregivers” refers to future or successor guardians.

The Need for Psychosocial Support During Permanency Planning

Permanency planning requires that mothers face their own mortality, which may be further complicated by feelings of guilt and the recognition that they may not see their children grow up. Additionally, HIV-positive mothers must face disclosing a stigmatized disease to family members, including children and potential future guardians. Due to the multi-generational nature of HIV, disclosure to children often leads to difficult questions about transmission, the mother’s sexuality and/or drug use, and death—their own as well as their mother’s. Reluctance to disclose, confusion about the future, and the struggle to cope with critical health needs frequently lead mothers to postpone permanency planning to the detriment of themselves, their
may not be able to accept the fact that the mother and/or a child have HIV.

Disclosing their HIV-status to children of any age can be challenging and painful for a mother. Disclosure to adolescents can be especially taxing as it is often a mandatory component of completing a permanency plan. In most states, children who are 13 or 14 years of age or older must agree to the proposed adoption, standby guardianship, or (in Illinois and Iowa) standby adoption. Completing a permanency plan can provoke questions from teenagers about the reasons for the plan and raise their fears about the future. Teens may also disagree with their mother’s choice of caregiver.

Although most guardianship and other legal planning laws do not require HIV disclosure, courts may require information as to the reasons for the legal “backup” plan. Many mothers are hesitant to disclose because they fear that their information may be shared in open court, potentially impacting their employment, insurance, housing, or immigration status. Reluctance to disclose may also stem from challenges emanating from the legal system, including, for example, judges and attorneys who are insensitive or who discriminate against HIV-positive parents.

The following case example illustrates how a mother’s reluctance to disclose her HIV-status can impede permanency planning, with profound repercussions for the family.

Case Example A: Disclosing in a Crisis

Julia, a mother of four, lived in Baltimore with two sons; the other children had died during infancy. When Julia’s health deteriorated following her HIV diagnosis and she became too disabled to care for her boys, she moved to Chicago to live with her mother, Edna. Shortly after relocating, Julia and her children, now three and four years old, were admitted to Chicago’s Cook County Hospital where both boys tested positive for HIV. Although her sons’ health improved, Julia’s status progressed to AIDS. Family Options staff met Julia in the hospital to help facilitate a disclosure discussion with Edna, necessitated by the boys’ need for ongoing medical care following discharge. Although Julia knew that disclosure was necessary, she was reluctant to talk to Edna. Immerged in simultaneously facing her own mortality, recognizing that she would not live to see her children mature into adulthood, grieving the two children she lost in infancy, and blaming herself for passing HIV during pregnancy to her two surviving children, Julia ultimately disclosed in a crisis. The same night that she told Edna about the HIV-positive diagnoses, Julia passed away. Shortly after his mother’s death, the oldest child died, as well.
Still in denial, Edna could not disclose the status of her daughter and grandsons to her husband until the oldest grandchild had died and she was receiving support from Family Options. Eventually, Edna mobilized herself so that she could meet the medical needs of her surviving grandson. The permanency planning process—including psychosocial and legal assistance—supported Edna in working through her grief so that she could become the legal guardian for her surviving grandson. It also helped her to negotiate the disclosure conversation with her husband.

This case study illustrates how HIV disclosure is inevitable and can become complicated by the deteriorating health status of a parent, as well as by the grief of the successor guardian. As discussed above, many obstacles can prevent a mother from disclosing her HIV status and completing a legal permanency plan. However, even under crisis circumstances, support and education from knowledgeable providers can help survivors cope with their grief and maintain family stability.

**Disclosure Services and Permanency Planning**

Ideally, disclosure support and counseling interventions begin when parents are physically and emotionally stable. Family Options’ method of disclosure planning normalizes stress for mothers and allows them to feel in control of the process, confront their fears, acknowledge their HIV status, and forge healthy relationships with their children.

The Family Options approach to HIV disclosure is to proceed at a pace set by the mother’s capacity to competently cope with the process and its potential aftermath. Empowering and collaborating with the mother, a clinical psychologist, serving as facilitator, provides a range of services:

- Offers practical education around a variety of social, health, and HIV factors; develops a resource list of peers and professionals who are well informed on topics that may arise during disclosure;
- Elicits a list of “disclosure players” (e.g., family friends, neighbors, counselors, clergy, school, medical, and judicial system personnel, and others) who may prove instrumental in short- and long-term outcomes for the family;
- Develops a list of issues that may arise during the disclosure process (e.g., death, HIV transmission, family drug history, sexual history and orientation) and assists in forming developmentally sensitive responses to each issue;
- Encourages mother’s self-assessment of readiness to disclose;
- Offers practical language for talking with children (how to start and how to continue);
- Develops a “star” list of family, friends, and professionals who are aware of the impact of HIV on the family, educated about HIV transmission, and empathetic to people living with HIV; and
- Raises awareness about disclosure as a process, not an event, and the need to plan for ongoing disclosure over time.

Additionally, the mother receives legal and other social support services during the disclosure and permanency planning process. This interdisciplinary approach can help empower a mother in making decisions that are in her children’s best interest.

The following case example illustrates an HIV-disclosure that was planned well in advance, with far more salutary outcomes.

**Case Example B: A Planned HIV Disclosure**

Rebecca was seven years old and unaware of her HIV-positive diagnosis when she first encountered the Family Options Project. Her mother, Jamie, had been unaware of her positive status when pregnant with Rebecca, and the child was born HIV-exposed. Jamie, who struggled with chemical dependency, was unable to care for her daughter, and Rebecca was removed from Jamie’s home by the Department of Children and Family Services (DCFS).
Disclosure as an Ongoing Process

HIV disclosure is an ongoing process that can impact a child’s need for permanency. For example, after a parent has died, the caregiver may need to disclose to others who have become significant to the family since the initial appointment of a standby guardian. These may include the caregiver’s new partner, the other parent who may have been absent or transient during the process of developing the original permanency plan, additional children or adults living in the home, and others who may be involved in managing the child’s medical care or social services. In addition, the original permanency plan can fall apart prior to implementation, usually due to changes in the new caregiver’s circumstances. In this event, a new permanency plan will need to be developed for the child, and the cycle of disclosure issues will begin anew.

Mothers will need to revisit HIV disclosure with their children as well. As children mature, they begin to ask more detailed questions about HIV. Times of maternal illness or deteriorating health also necessitate revisiting disclosure. Professionals can support an HIV-positive mother by reframing ongoing disclosure so as to normalize it as part of the parenting process. Disclosure does not have to mean that a mother is revealing weakness to her children. Rather, she is being a responsible parent by communicating with them, planning for their future, and revealing her HIV-positive status (or her child’s status) in a loving and supportive environment. By facilitating an open and ongoing family dialogue, social and legal service providers can empower a mother to cope with her diagnosis. In so doing, she can plan for the future care and custody of her children.

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Challenges for Future Caregivers

Disclosure of a child’s HIV status can impact a future caregiver’s decision to take responsibility for a child. Questions to be addressed in the decision-making process include:

* If the child is HIV-positive, is it in the child’s best interest for the future caregiver to become the guardian or standby guardian? Can the future caregiver manage HIV medication, HIV information, the stigma of HIV, and the child’s grief and loss issues around losing a parent to HIV, in addition to managing the “normal” parenting tasks of raising a child or adolescent?

* When the future caregiver is a grandparent, is she prepared to take on the care of a grandchild while struggling to deal with the loss of her adult child to HIV/AIDS?

* Does the caregiver have someone to whom she can disclose information about the HIV status of the child and/or the child’s deceased parent who is willing and able to act as a “backup” caregiver? Family Options recommends that the caregiver also make a legal “backup” plan for the child once she assumes legal responsibility.
“A lucha por mis hijos” (“to struggle for my children”) is often stated by Latino mothers as their paramount motivation for living after being diagnosed with HIV. However, the plight of these mothers has rarely been investigated in spite of the fact that Latinas comprised 14% of deaths due to AIDS and 15% of newly reported AIDS cases in 2006 (Centers for Disease Control and Prevention [CDC], 2008). Additionally, Latinas are second only to African American women in their overrepresentation in HIV prevalence rates.

Research has suggested that the interplay of cultural factors, disclosure, and HIV is complex and must be understood in order to provide culturally competent services to Latinas (Amaro & De la Torre, 2002; Moreno, 2007; Scott, Gilliam, & Braxton, 2005). However, to date, the racial and ethnic influences on maternal disclosure have been understudied and have also yielded mixed results. For example, stigma, perceived discrimination, secrecy, and feelings of being devalued have been associated with nondisclosure to children among African American, Latino, and White non-Hispanic mothers, but without any clear ethnic or demographic differences (Letteney & LaPorte, 2004). In contrast, in a study of maternal HIV disclosure and mental health, foreign-born (immigrant) Latino mothers reported higher levels of anxiety and depression compared to African American mothers (Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007).

Only a small number of studies have focused exclusively on disclosure to family members by HIV-positive Latinas (Moreno, 2007; Simoni et al., 1995). Although some studies describe the outcomes of maternal HIV disclosure to children and families (e.g., Murphy, 2008; Tompkins, 2007), the direct effects on Latino children have not been clearly delineated.

Nuestras Familias Project

The Latino Family Institute prides itself on its pioneering work with the Latino community in Southern California and for offering services that are culturally relevant and guided by the values and beliefs of the community it serves. Since 2005, Nuestras Familias (Our Families), an AIA-funded project sponsored by the Institute, has served HIV-positive Latino mothers and their children (0-6 years old), targeting the role strains associated with immigration and acculturation.

Project participants are low acculturated, monolingual Spanish-speaking immigrants living in poverty or in multiple family households. Having migrated to the United States from Mexico (82%), Central (7%) and South America (11%), they have resided in the city of Santa Ana, in close proximity to the U.S.-Mexico border, for an average of ten years. Almost all (97%) are heterosexual women who became infected with HIV through sex with male partners, as have growing numbers of women nationally (CDC, 2008). Their socio-demographics include poverty (81%), isolation (71%), low educational attainment (9 years on average), unemployment (68%), limited job skills (75%), and substandard housing (73%). Over two-thirds of the mothers have reported histories of childhood

Research has suggested that the interplay of cultural factors, disclosure, and HIV is complex and must be understood in order to provide culturally competent services to Latinas.
abuse (67%) and intimate partner violence (71%). Due to their immigrant status and language barriers, these women have had poor access to health care, limited knowledge of health resources, and no medical insurance. At program enrollment, they have often reported a poor quality of life, depressed mood, and stress in parenting.

Despite the bleak circumstances presented by Latino mothers, Nuestras Familias has made significant strides in providing clinical and psycho-educational interventions that have effectively reduced their mental health problems. The project has also developed an understanding of culture-specific barriers to disclosure for Latina mothers and found ways to address them, as described below.

**Barriers to Disclosure**

A number of cultural factors function as barriers to disclosure in Latino communities. For one, “SIDA” (AIDS) carries with it profound stigma. Disclosure threatens the women’s self esteem by raising suspicion of drug abuse or promiscuity and causing shame and embarrassment. Consequently, Latino mothers are reluctant to disclose their HIV status and also receive little social support for coping with the disease (Amaro & De la Torre, 2002; Moreno, 2007; Pérez-Jiménez, Seal, & Serrano-García, 2009).

Additional cultural factors, such as low acculturation and immigration status, also pose obstacles to disclosure. Latino mothers’ willingness to disclose can be affected by discriminatory laws preventing access to treatment, the threat of deportation, high levels of poverty, and low education levels (Carmona, Romero, & Loeb, 1999; Moreno, 2007). Problems with disclosure are also linked to traditional sex roles, intimate partner violence, and substance abuse (Amaro & Raj, 2000; Gómez, Hernández, & Faigeles, 1999; Moreno, 2007; Wyatt et al., 2002; Zambrana, Cornelius, Boykin, & Lopez, 2004).

In providing services to immigrant HIV Latino mothers, Nuestras Familias has found that many of them endure intimate partner verbal and physical abuse out of the need for economic support or immigration documents, and particularly because they fear being ostracized from their community. As a result, they are reluctant to disclose their HIV status and, despite the need to establish formal guardianship plans for their children, few of the women have done so.

Three cultural determinants—traditional sex roles, cultural ideals of motherhood, and religion—can be particularly potent impediments to HIV disclosure for Latinas, and all three were found to be operative barriers for the mothers in the project.

**TRADITIONAL SEX ROLES**

Grasping the impact of traditional sex roles is critical to understanding HIV disclosure among low acculturated Latino mothers, especially because traditional male sex roles are more likely practiced by low acculturated men (Pérez-Jiménez, Seal, & Serrano-García, 2009; Scott, Gilliam, & Braxton, 2005).

The concepts of Machismo and Marianismo, rooted in Spanish Catholicism and gender construction, play important parts in defining gender among Latino men and women. In general, the word “macho” in its original form was meant to describe a “real man”—one who is hard-working, responsible, and caring to his family, children, and community. In contrast, Machismo has often ascribed Latino men as inflexible in both male-male and male-female relations, violent, and exerting virility onto women. Because this negative view has prevailed in the American mass media, the original ideal has often been lost.

The epitome of Marianismo, the female counterpart to Machismo, is the pure, honorable, and selfless Virgin Mary. Marianismo is an ideal that traditional and low acculturated Latina women are expected to uphold through their attitudes, beliefs, and behaviors. Moreover, Latinas are socialized to be self sacrificing for their husbands or partners and children and to endure infidelity.

The direct relationship between traditional sex roles and disclosure of HIV among Latino mothers has not been thoroughly examined (Amaro & De la Torre, 2002; Simoni et al., 1995). However, a number of negative outcomes for infected Latino mothers have been associated with traditional sex roles. First, low acculturated Latinas experience intimate personal violence that is often exacerbated by disclosure of HIV (Moreno, 2007). Second, traditional sex roles may underscore the inability of heterosexual Latinas to protect themselves from being infected because of the culturally sanctioned expectations of sexual purity and sexual naiveté (Amaro & De la Torre, 2002; Moreno, 2007; Scott, Gilliam, & Braxton, 2005). Third, isolation linked to immigrant status has been associated with HIV stigma in the Latino community (Marín & Marín, 1990; Pérez-Jiménez, Seal, & Serrano-García, 2009). Disclosure among immigrant Latino mothers has also been related to levels of social support; mothers with poor social support are less likely to disclose.

**THE NATIONAL ABANDONED INFANTS ASSISTANCE RESOURCE CENTER • THE SOURCE VOL. 19 NO. 2**
Nuestras Familias’ Culturally Competent Approach

The positive HIV mothers served by Nuestras Familias subscribe to traditional sex roles and the maternal ideals of Marianismo and, for many women, strict Catholicism. In developing culturally sensitive services for this population, the project has applied service strategies that emphasize the importance of Latino values and beliefs and reflect an awareness of traditional sex role practices and their potential impact on disclosure. Nuestras Familias provides health education and support groups that assist the women in learning about HIV/AIDS, coping with the perceived stigma of the disease, and addressing traditional cultural beliefs that may pose barriers to disclosure.

For example, one educational intervention involves displaying a pile of unwrapped condoms and asking the mothers to describe different categories of at-risk persons who should be using protection. The activity has been successful in opening up discussion about the fears of revealing their HIV status while increasing their knowledge of disease transmission.

The mothers also participate in support groups to share their economic hardships, acculturation stress, and emotional distress. A Nuestras Familias’ project clinician uses problem-solving techniques and role plays to help the mothers cope with their feelings about disclosing to their children and for some, their partners. It should be noted, however, the mothers are never pressured into disclosing their status.

The program’s interventions incorporate universal cultural values by honoring the Latino family: mothers, fathers, children, and extended families. Social and recreational structured activities bring participant families together as a collective community to celebrate traditions and customs, including Mother’s Day, a children’s Easter egg hunt, and “Los Tres Reyes” (The Three Kings), a Christmas celebration. These activities are used to increase social support among the program’s isolated immigrant families. At times, Latino mothers have used these safe and structured opportunities to informally disclose their HIV status to extended family and friends.

Nuestras Familias provides alternative views and practices to counteract the mothers’ feelings of failure when they cannot meet the cultural ideals of motherhood. For example, Latina mothers place a high value on breastfeeding and express a sense of loss when they are unable to nurse because of the disease. The project counters feelings of failure by teaching them infant massage as a way to enhance bonding with their babies and reinforce their sense of self as good mothers. Nonetheless, the women still risk

CULTURAL IDEALS AND RELIGION

The role of Latino cultural ideals in creating barriers to disclosure is illustrated in the migration process. In a large national sample of 2,554 Latino and Asian respondents, the primary reason for migration to the United States was to better the lives of their children (Guarnaccia et al., 2007). This view is related to the culturally sanctioned maternal ideal, which in turn is rooted in traditional sex roles and Marianismo. Latinas in their roles as mothers are ascribed reverence and adulation and internalize high culturally sanctioned maternal standards. When these standards confront the reality of a stigmatized disease that threatens their capacity to uphold them, immigrant mothers often feel that they have failed their children, preventing them from achieving the American dream. From this perspective, disclosure threatens the risk of additional feelings of failure and guilt.

Catholicism brings with it a long history of religious traditions and beliefs that can affect disclosure. Some Catholics believe that they must “cargar nuestra cruz” (“carry our cross”), which can translate into bearing their diagnosis with stoicism and silence. In addition, Catholics may believe that their diagnosis is a punishment from God, an idea further perpetuated by the stigma of HIV. Fearing rejection by the church can reinforce the tendency against disclosure.

Latinas in their roles as mothers are ascribed reverence and adulation and internalize high culturally sanctioned maternal standards.
unintended disclosure when family members ask them why they are not nursing. The mothers have difficulty dealing with these situations and, if unprepared to disclose, tend to explain that the baby is allergic.

The Catholic Church plays a central role in the lives of most Nuestras Familias’ families. The project respects that role by including priests in the program’s recreational activities and supporting family involvement in the Church. However, disclosure of HIV to children is not sanctioned by the Church, and women often fear rejection by their priests. Nuestras Familias encourages the mothers to seek out progressive priests who are supportive and willing to challenge some traditional beliefs. The project also helps mothers reframe restrictive or punitive religious beliefs. For example, viewing their HIV as “carrying the cross” is reframed as the possibility of becoming “stronger” in “carrying the cross” by learning to advocate for themselves, their HIV medical treatment, and/or communicate about their illness.

Understanding the cultural aspects of disclosure is a critical component in providing culturally competent services to Latina mothers living with HIV. Nuestras Familias has done groundbreaking work in identifying traditional sex roles, cultural ideals, and religion as barriers to disclosure and in developing approaches to address them with sensitivity and respect. However, further research and program development are needed before the needs of this seriously challenged population will be adequately met.

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The Philadelphia Story

In 2007, Philadelphia recorded the largest number of people living with HIV/AIDS in the city’s history. The rate of infection is now estimated at 114 for every 100,000 people, five times the national rate of 23 per 100,000 (AIDS Activities Coordinating Office [AACO], Philadelphia Department of Public Health, 2009). In 2007-2008, women accounted for 40.6% of newly diagnosed cases in Philadelphia, and 14,840 infected women of childbearing age were residing in the city, a significant increase from prior years. While perinatal transmission has become almost non-existent nationally, and women who are compliant with their medication regimen are living much longer, AACO reported ten new perinatal transmissions in 2008–2009 in Philadelphia, compared to only one in 2007.

The impact of HIV is profound and multi-dimensional for infected women, their families, and communities. Mothers living with the disease while raising children face physical and emotional challenges, including deteriorating health, stigma and social isolation, disclosure issues, compliance with medical treatment, and future care and custody planning. The additional challenges of poverty, inadequate housing, gender imbalance, incarceration, historical and persistent trauma, and, in some cases, addiction can be overwhelming (Gilbert, 2009), placing mothers and children at great risk for a range of mental health disorders and behavioral problems (Radcliffe et al., 2007; Siever, 2008; Tomaszeski, 2001).

The Health Federation of Philadelphia’s Family Centered Home Visitation Program (FCHVP) was developed in 1991 to address the needs of HIV-positive women and their children in the inner city. After briefly presenting the FCHVP model of care, this article will describe The Writing Project, an innovative healing arts project.

The Writing Project: “Telling Our Stories”

Just because I am positive

Doesn’t mean I am a negative person
Just because I am positive
Doesn’t mean I can’t be a good friend
Just because I am positive
Doesn’t mean I forgot how to love
Just because I am positive
Doesn’t mean I’m not blessed from above
Just because I am positive
Doesn’t mean you cannot be a good friend
Just because I am positive
Doesn’t mean I can’t be a mommy
Just because I am positive
Doesn’t mean I can’t be a person
Just because I am positive
Doesn’t mean that I can’t be me
Or be free to explore the complexities
Of life and come through
With all of my capabilities

Roseanna, mother of an eight year old daughter

Maria C. Frontera, MSW, LSW, Valerie Anderson, MSW, LSW, Kathryn Stein, BSW, and Una Majmudar, LCSW

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The Writing Project consists of a series of individual and group psycho-educational experiences using poetry, prose, art, photography, and performance to provide an outlet for women’s feelings in response to HIV. The goal is to enhance women’s ability to integrate the disease into their lives through self-discovery and self-expression, while increasing coping strategies.

The Project has two components: a women’s support group called Celebration of Life, and an expressive arts experience, I See Beauty in These Streets. Only mothers participated in Celebration of Life. I See Beauty in These Streets primarily engaged women but also included a small number of men. In total, thirty mothers have participated in The Writing Project since its inception.

CELEBRATION OF LIFE

This support group employs creative writing to help women describe, celebrate, and heal their lives, express feelings, connect with others, and explore the gifts and challenges of living with HIV. Meeting for two hours three times a month, the group is facilitated by two Masters level licensed social workers (Mental Health Specialists) certified in trauma-sensitive practices. Facilitators share works of poetry and prose and use specific queries to assist and support participants as they write and share their thoughts and stories. For example, the poem “Dream Deferred” by Langston Hughes (1951) was used as a prompt, followed by the question: “What were my dreams before being diagnosed with HIV and what are my dreams after diagnosis”? Lucille Clifton’s (1987) poem, “Homage to my Hips,” prompted the writing of poems exploring and celebrating the body. The exercises in John Fox’s (1997) Poetic Medicine prompted women to find the words which most closely describe how they feel. One mother wrote: “Peaceful, Furious, Absorbed, Clouded, Determined, Life.” Additionally, with the help of a local poet, Gweny Love, the women performed their writings in a “choreo-poem” presentation for an audience of social service providers.

Home Visitation Program, created The Writing Project in 2005 to address mothers’ psychosocial needs. A premise of the project is that people with HIV need to have their voices heard, and that writing and reading their stories in their own voices can be life-altering. The Writing Project is based in part on narrative therapy, which holds that stories shape identity and convey people’s inner worlds and the ways they understand themselves and their experiences (Jones & Broth, 2009). Moreover, the process of telling personal stories, whether verbally or through writing, art, movement, visualization, or other forms of expression, can be profoundly healing, especially when stories involve traumatic or challenging events (Miller, 2003; National Abandoned Infants Assistance Resource Center, 2006; Pennebaker, 2004).

The FCHVP Model

The FCHVP offers a full range of home-based, culturally competent, accessible, and trauma-informed services to low-income HIV- and AIDS-infected pregnant and parenting women (13 years and older), their infants and toddlers (0-3 years), and their families. Ninety-five percent of clients are African American, the majority of whom are single mothers. A small number of fathers have also been served.

Services include: child development and parenting support; mental health treatment; health/nutrition monitoring, including treatment adherence; coordination of services with medical case management; and referrals to early intervention for developmental delays, as well as to educational, legal, and community social services. A multidisciplinary team (family advocates and mental health specialists), in collaboration with a consortium of community-based organizations, delivers the services.

Mental health is a primary program focus. Interventions center on mother-child relationship-building and increasing mothers’ ability to access and utilize formal and informal support systems for themselves and their children. Based on a family’s assessed level of strength and need, treatment may include individual and family counseling, psycho-educational and psychotherapeutic groups for adults, and, when necessary, crisis management. To promote emotional attunement, services often begin with helping participants identify, and learn to appropriately discuss and express, their feelings with greater comfort. One way to do that is through writing.

“Telling Our Stories”

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One mother wrote the following for her child:

“You are my world. You know I love you with all my heart. We share everything together. You know that Mommy is not going to be here 4-ever and I want you to always be the same strong, sweet, happy little boy that I know and love. You have to stay sweet for me and take care of everybody who takes care of you. You have touched so many hearts in the past short life you have lived. You are so special to me and everybody you touch. I wish it wasso much [more] I can do for you, but tomorrow is not promised to us so you know I do the best I can do with what I have. So don’t change nothing about you and that you are loved always by people everywhere. God loves us. Love, Mommy”

Jakella, mother of a six-year-old son

Examples of writing prompts and participant responses follow:

- **What does creativity mean to me?** “Creativity is a part of the soul that allows communication to others.”
- **What is beauty to me?** “Beauty is either external or internal. External beauty is often fleeting and dated.”
- **What am I learning of beauty?** “I learn that beauty is found in some of the most unusual places.”
- **How do I feel?** “When looking for beauty in the inner city, it makes me feel more connected to the world.”
- **What am I discovering about myself?** “I am discovering that my self-esteem is extremely low. For whatever reason, I feel that no one will find me worthy of love anymore. It could be all of the medical issues and there is no wish for the future. It is not a productive way to live life by resting on your laurels of accomplishments.”

Over the weeks, participants discuss the experience of writing and taking photographs. Discussion topics include: health/illness; nature; relationships with the community; isolation; spirituality; recovery; the arts; and violence. Group members are encouraged to become “peer mentors” or co-facilitators in the sessions.

Pre- and post-tests are given during the first and last sessions. Evaluation questions explore feelings (physical, emotional, spiritual), levels of connectedness to self, families, friends, and community, safety in their community, and use of creative outlets. Participants have reported an increased sense of awareness, well-being, and connection to self, others, and the environment: “It has opened my eyes to beauty around me.” “Allows me to see beyond myself.” “With the illnesses I have, the society at large still sends a lot of signals of stigma. When walking through the city and seeing beauty, it assists in making me feel more connected again to the world and others, as well as less stigma.”

**I SEE BEAUTY IN THESE STREETS**

The second component of The Writing Project was conceived in 2007 by Kathryn Stein, former FCHVP Family Advocate, in collaboration with SILOAM, a spiritual center for people with HIV. Participants are helped to find beauty and hope in their everyday lives by using photography and journaling (written or visual) to express their feelings, thoughts, and experiences and to improve their connections to the community. During the first session of a five-week experience of discovery, foundations of photography and journaling are taught. Each participant receives writing and photo prompts, a blank journal, and a copy of *Soul Talk: Urban Youth Poetry* (Montero, 2007), a collection of writings and photographs of the community from Syracuse City School District students. The book serves as inspiration and as a demonstration of expressions about courage and overcoming adversity. Participants are also given disposable cameras with the instruction to photograph the world around them and journal about the experience.
Participants also organized a public exhibit of their work and were able to share thoughts, feelings, and future goals with the audience. The following is an example from the exhibit:

**Community**

When you look within this picture, what do you see?
Lift your eyes to expand your horizon through your imagination.
For I see old and new, the recreating of life.
The recycling of the old within the new.
I see a rich heritage within the earth of God’s creation, a great respect of the world.
I see love, honor, wealth, family, nature and I can go on.
But the most important thing I see and think within the taking of this assignment is life within itself and others.
Yes! I do see beauty, the recreation of beauty of within.

_Yema, mother of four children_

**Program Evaluation**

Comfort Consults designed and has conducted the Family Centered Home Visitation Program evaluation since 2006. Seventy percent of mothers in The Writing Project have participated in the evaluation. Preliminary data shows significant improvement in participants’ well-being as demonstrated by increased social support, decreased symptoms of depression, and strengthened parent-child relationships. In the words of one mother, “The program gave me the wings to fly out of a state where I thought I was going to die.”

Specific data continues to be gathered through standardized assessment instruments:

**Center Epidemiological Studies Depression Scale (CES-D)** (Radloff, 1977)

This 20-item self-report scale was designed to measure depressive symptoms in the general population experienced during the past week. Staff uses the scale to identify parents’ needs, refer for mental health care, monitor depression, and assess outcomes. If a positive CES-D is obtained, staff will administer the assessment monthly.

- 48% of mothers who exhibited symptoms of depression at intake improved.

**Life Skills Progression (LSP)** (Wollesen & Peifer, 2006)

LSP is a 43-item comprehensive rating scale designed for home visits with low-income families with children (0-3 years) to assess family functioning in seven areas: relationships, parenting, physical health care, mental health/substance abuse, child development, education, employment, and basic needs. In addition, FCHVP uses the scale to identify family strengths and needs, plan family goals, and measure outcomes in functional health literacy and parent-child well-being.

- Comparisons of the Life Skills Progression (LSP) **Personal Health Literacy Cluster** during program enrollment showed significant increases in personal health behaviors (e.g., smoking cessation, lack of substance abuse, self esteem) and support for children’s safety and healthy development.
- Comparisons of the LSP **Relationships Cluster** during program enrollment showed statistically significant positive changes in relationships with family and friends, i.e., increased social support.

**Keys to Interactive Parenting Scale (KIPS)** (Comfort & Gordon, 2006)

KIPS is a 12-item observational rating scale designed for family service providers to assess 20 minutes of videotaped free play between a caregiver and child 2-71 months in the home or familiar setting. KIPS assesses the quality of parenting by identifying parenting strengths and needs, developing parenting goals and strategies, tracking family progress, and evaluating parenting outcomes. Staff uses the scale to set parent-child relationship goals, link to the parenting curriculum, track progress in the quality of parenting, and assess outcomes.

- 84% of parents demonstrated a satisfactory quality of parenting behaviors adapted to the needs of their children. For families with an initial score indicating parenting concerns, a statistically significant increase in the quality of parenting was documented at follow-up. Findings reflect more effective parenting behaviors and stronger parent-child attachment.
My Voice is Heard

I look at the world
And I see how bright
And then I know I can’t
Give up without a fight

Speak out
Hear my voice so loud
Let everyone know
I’m proud of who I am
And what I stand for

I’m not sad for the sorrows
I endured
They make me strong
They make me strive
They make me want
2 stay alive

One person,
One mind,
One more heart
I can reach

If I’m lucky
They will listen
2 my speech,
Because I was once
Just like U
Lost, crying
Not knowing what to do
Speak

RoseMarie, mother of two daughters

Conclusion

Many people living with HIV have responded with isolation, silence, and depression to the pervasive and painful social stigma associated with the disease. The Writing Project empowers women to discover their inner strengths and to see themselves as more than mere vectors of disease. In so doing, they embrace the totality of their being and re-engage with broader aspects of themselves, their children and families, and their community. The Writing Project gives voice to their new-found courage and presence and ensures that their words will live on.

REFERENCES


This article is dedicated to all those who participated in The Writing Project.
Books, Guides, and Reports

Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses

Ground-breaking book focuses on the experiences and perspectives of children who care for a parent with HIV. Drawing on original research, it presents insight into the similarities and differences in children’s experiences across diverse socio-economic, cultural and welfare contexts. Examines the impacts of caregiving; children’s and families’ resilience; the factors influencing whether children become involved in care work; and local and global policy responses. Cost: $39.95.


A Guide to the Clinical Care of Women with HIV

Addresses the health care needs unique to women with HIV. Targets clinicians who provide primary care to women, as well as those seeking an understanding how to take care of them. Includes tables, figures, resources, references, and indices. Cost: Free online.


Positive People: Combating HIV and AIDS

Collection of stories and poems of people infected with, or affected by HIV and AIDS reflects the personal experience of one of the co-authors (Wyatt-Morley). Book highlights the problems of people of color gaining access to health care, and discrimination against women in medical matters. Appendix gives health advice, statistics, and resources. Cost: $15.50.


The End of Stigma? Changes in the Social Experience of Long-Term Illness

Investigates the roots of contemporary experiences of stigma, throwing new light on the phenomenon by examining a variety of long-term conditions including HIV, mental illness and substance misuse. Award winning author, Gill Green, demonstrates that people with long-term conditions refuse to be defined by their condition, and highlights their increasingly powerful voice. Cost: $43.95 (soft copy); $140.00 (hard copy).


The Psychological and Social Impact of Illness and Disability: 5th Edition

Retitled new edition emphasizes an illness, as well as a disability trajectory, and its impact on an individual’s well being. Highlights the personal stories of those faced with the many demands of living with a disability. Will help the reader become aware that making a connection between relevant theory and insightful practice results in a more enhanced quality of life for all individuals living with disability. Cost: $85.00.


Communication Perspectives on HIV/AIDS for the 21st Century

Up-to-date collection focuses on today’s key communication issues in the HIV/AIDS epidemic. Chapters examine the interplay of messages individuals receive about AIDS at the public level, as well as the interpersonal level. Includes examples that showcase the diversity of approaches to health communication used to combat the HIV/AIDS epidemic. Cost: $42.95 (soft copy); $110.00 (hard copy).


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Coping with Chronic Illness and Disability: Theoretical, Empirical, and Clinical Aspects

Individuals’ responses to their chronic illness or disability (CID) vary widely. This book synthesizes the literature on coping styles by analyzing how individuals with CID face challenges, find and use their strengths, and alter their environment to fit their life-changing realities. Includes: current information on coping with conditions such as: cancer, heart disease, HIV/AIDS, and severe mental illness; coverage of therapeutic modalities for treatment of people with CID; review of the current state of coping theory and research; and an appendix of instruments frequently used in coping assessment. Cost: $99.00.


The Home Visitor’s Guidebook: Promoting Optimal Parent & Child Development

The ultimate professional development resource for early interventionists, social workers, therapists, and other home visitors, this research-based guidebook is enhanced throughout with up-to-date references and new material on today’s hot topics. Readers will learn the basics of effective home visiting: building trust with families, communicating effectively, maintaining boundaries, working with families experiencing risk factors, and integrating professional beliefs with families’ cultural beliefs. Cost: $44.95.


Videos & Teaching Kit

The Complete HIV/AIDS Teaching Kit with CD-Rom

Offers an overview of what science knows about the incidence, prevalence, antecedents, consequences, prevention, and treatment of HIV/AIDS. Addresses the behavioral and sociocultural influences that both facilitate and prevent the spread of HIV. Cost: $245.00.


Positive Dreams

Video featuring story-telling, comedy, music and dance to address the fears, hopes, achievements and dreams of women living with HIV. Twice a week for ten weeks, “BABES” and staff gathered to learn movement techniques, practice voice exercises and workshop material for a community-wide performance about women and HIV. The “Theater for Development” workshops were full of laughter, fear, silliness, anger, courage, tears, exploration, dancing, singing, hugs, and sisterhood. Cost: $10.00.


Internet Resources

Avert

www.avert.org. Information on prevention, transmission and infection, treatment and care, and education.

The Body


HIV/AIDS Stigma


HIV InSite


National Minority AIDS Council’s HIV/AIDS Stigma Program


National Prevention Information Network (NPIN)


Positive Lives

www.positivelives.org. Documents the impact of the global HIV epidemic through photography. Website includes stories and testimonies of people living with HIV, further information and resources.

POZ

www.poz.com. Publishes a variety of health care resources, (i.e., POZ magazine) to inform people with AIDS, their families, friends, caregivers and others in U.S. and overseas.

Project Inform

www.projectinform.org. Offers fact sheets, in-depth discussion papers, and publications, many of which are available in Spanish. Wide range of topics addressed, (e.g., anti-HIV therapies, diagnosis and treatments for HIV/AIDS-related diseases and conditions, health care access, and treatment discussions).

The Well Project

www.thewellproject.org. Includes information on HIV basics, treatment, trials, disease, conditions, and living well with HIV. Also features discussion groups for women to share their experiences with one another.

Women Organized to Respond to Life-threatening Diseases (WORLD)

www.womenhiv.org. An information and support network by, for, and about women with HIV/AIDS. Site offers access to WORLD’s newsletter, fact sheets, materials, as well as information about their peer education and advocacy program and retreats.
Conference Listings

5th National Conference on Health and Domestic Violence

This biennial conference aims to advance the health care system’s response to domestic violence. It attracts the nation’s leading medical, public health and family violence experts from across the U.S. with increased international participation. The latest research and most innovative clinical responses to domestic violence will be highlighted, with a focus on the work being done by physicians, physician assistants, dentists, nurses, nurse midwives, mental and behavioral health providers, social workers, domestic violence experts, and others.

Dates: October 9-10, 2009
Sponsor: Family Violence Prevention Fund
Location: New Orleans, LA
Contact: www.fvpfhealthconference.org

Alliance National Conference

This conference offers participants the opportunity to experience the best in networking, professional development, and intellectual stimulation through 50 workshop options, social events, and keynote speakers. The workshop tracks cover governance, innovative programs, leadership, management, and other topics of interest to CEOs, senior management, board members, and key staff at child and family serving agencies.

Dates: October 14-16, 2009
Sponsor: Alliance for Children and Families
Location: Houston, TX
Contact: http://www.alliancecr.org

2009 United States Conference on AIDS

The largest AIDS-related gathering in the United States, over 3,000 workers from all fronts of the HIV/AIDS epidemic—including case managers, physicians, public health workers and advocates, people living with HIV/AIDS, and policymakers—come together to build national support networks, exchange the latest information and learn cutting-edge tools to address the challenges of HIV/AIDS.

Dates: October 29-31, 2009
Sponsor: National Minority AIDS Council (NMAC)
Location: San Francisco, CA
Contact: http://www.nmac.org/index/2009-usca

Association for Medical Education and Research in Substance Abuse (AMERSA)’s 33rd National Conference

The conference is notable for its in-depth focus on substance abuse education and the high quality of its workshops and presentations. Its objectives are to bring together researchers and professional health educators to learn about scientific advances and exemplary teaching approaches. AMERSA’s membership is multidisciplinary, comprised of physicians, nurses, social workers, dentists, psychologists, public health practitioners, substance abuse specialists, physician assistants, and allied health professionals.

Dates: November 5-7, 2009
Sponsor: AMERSA
Location: Bethesda, MD
Contact: http://www.amersa.org/conf.asp

The International Society for Traumatic Stress Studies (ISTSS) 25th Annual Meeting

This is an international gathering of professionals and students—psychiatrists, psychologists, social workers, nurses, counselors, researchers, administrators, advocates, journalists, clergy and others—representing an array of disciplines related to the study and treatment of traumatic stress. This year’s meeting theme is “Traumatic Stress Disorders: Toward DSM-V and ICD-11.” The primary objectives are to provide a forum to consider how to define and conceptualize problems of posttraumatic adjustment with an eye toward upcoming revisions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) classification systems, and to facilitate an exchange of ideas about the reciprocal process by which diagnostic nomenclature influences science, clinical services, policy, advocacy and vice versa.

Dates: November 5-7, 2009
Sponsor: ISTSS
Location: Atlanta, GA
Contact: http://www.istss.org/meetings/index.cfm
The 2009 International Drug Policy Reform Conference
This meeting connects the dots between and among the full spectrum of drug policy issues within communities and around the world. Participants will learn the latest about alternatives to incarceration and harm reduction innovations; engage in debates about law enforcement and treatment; hear from leading writers and thinkers about the history and future of psychoactive drugs; and find out what’s happening in drug policy reform locally, nationally and globally.
Dates: November 12-14, 2009
Sponsor: Drug Policy Alliance
Location: Albuquerque, NM
Contact: http://www.reformconference.org

National Perinatal Association (NPA) 2009 Clinical Conference & Exhibition
The theme of this conference is “Focusing on the Family” and will cover models of care and research on topics related to the evolution of perinatal health, preconceptional care, and improving outcomes for mothers, fathers, and infants.
Dates: November 12-14, 2009
Sponsor: NPA
Location: Fort Worth, TX
Contact: http://www.nationalperinatal.org

International Association of Physicians in AIDS Care (IAPAC) 09: Unity in Action
This abstract-driven conference will feature 72 oral abstract presentations as well as poster presentations. Abstract-driven sessions will address issues in two tracks: HIV Clinical Management (Track A) or HIV Prevention, Testing, and Psychosocial Support (Track B). The conference will also feature a keynote address, plenary presentations, a panel discussion, interactive case-based sessions, and satellite symposia. The intended audience includes physicians, pharmacists, physicians in training, nurses, psychologists, social workers, advocates, healthcare alliance coordinators, and allied healthcare professionals in the fields of HIV and AIDS.
Dates: November 29 - December 1, 2009
Sponsor: IAPAC & The Foundation for AIDS Research (amfAR)
Location: New Orleans, LA
Contact: http://www.iapac.org/IAPAC09

National Federation of Families for Children's Mental Health 20th Anniversary Conference
“Children’s Mental Health Matters” is the theme for this conference, a celebration of family involvement, expansion of the Federation of Families, and two decades of committed individuals, families, and communities. This conference will focus on how families and their partners are successfully promoting children’s mental health.
Dates: December 3-6, 2009
Sponsor: National Federation of Families for Children’s Mental Health
Location: Washington, DC
Contact: http://www.ffcmh.org

24th National Training Institute (NTI) of ZERO TO THREE
This comprehensive and multidisciplinary conference focuses on cutting-edge research, best practices, and policy issues for infants, toddlers and families. The NTI attracts multidisciplinary professionals working in mental health, early intervention, early care and education, child welfare, family support, social services, and health care.
Dates: December 4-6, 2009
Sponsor: ZERO TO THREE
Location: Dallas, TX
Contact: http://www.zerotothree.org/site/

This conference will feature at least 50 workshops, two keynote presentations, a number of networking opportunities, poster sessions, and special engagements. Presentations will highlight evidence-based strategies and successful models for their implementation. A broad range of child welfare issues will be covered, including adoption, foster care, mental health, public policy, and youth in transition.
Dates: January 25-27, 2010
Sponsor: CWLA
Location: Washington, DC
Contact: http://www.cwla.org/conferences/conferences.htm

24th Annual San Diego International Conference on Child and Family Maltreatment
This conference focuses on multi-disciplinary best-practice efforts to prevent, if possible, or otherwise to investigate, treat, and prosecute child and family maltreatment. The objective of the conference is to develop and enhance professional skills and knowledge in the prevention, recognition, assessment and treatment of all forms of maltreatment including those related to family violence and substance abuse as well as to enhance investigative and legal skills. Issues concerning support for families, prevention, leadership, policy making, and translating the latest research into action are also addressed.
Dates: January 25-29, 2010
Sponsor: Chadwick Center for Children & Families
Contact: San Diego, CA
Contact: http://www.chadwickcenter.org/conference.htm

National Leadership Conference on Child Welfare Issues (NLCCWI)
The NLCCWI brings together high-performing child welfare leaders from across the country to discuss critical issues facing the nonprofit human services sector. Each year, a planning committee of Alliance peers selects a new theme to drive the focus of the conference. The conference is known for its quality content and premier networking opportunities with both experts and experienced peers.
Dates: April 26-27, 2010
Sponsor: Alliance for Children and Families
Location: Boston, MA
Contact: http://www.alliance1.org
Visit the National AIA Resource Center at
http://aia.berkeley.edu

Website Features

- Numerous monographs, fact sheets, issue briefs, and other publications—most of which are available for free download in PDF format
- Archived issues of The Source from 1993—present available for download
- Information about Resource Center trainings and conferences, including our ongoing Teleconference training series
- Archived proceedings from past Resource Center trainings and conferences, including recordings and handouts
- Profiles of federally funded Abandoned Infant Assistance (AIA) projects

The site also features extensive information and resources about families affected by HIV and/or substance abuse, including special topics such as:

- Kinship Care
- Standby Guardianship and Future Care and Custody Planning
- Shared Family Care
- Substance Exposed Newborns
- Child Welfare

To receive periodic emails from the Resource Center announcing new publications, conferences, and trainings, and other important information, email aia@berkeley.edu and ask to be added to our email list.
Announcing a National Summit on Substance Exposed Newborns!

**Substance Exposed Newborns: Collaborative Approaches to a Complex Issue**

**When:** June 23-24, 2010  
**Where:** Alexandria, VA  
**What:** Interdisciplinary dialogue, information sharing, and exploration of policies and collaborative approaches to prevent, identify, and address the needs of substance exposed newborns.  
**Who:** Administrators, policy makers, direct service providers from fields of substance abuse, child welfare, maternal and child health, obstetrics, pediatrics, nursing, social work, courts, and early intervention  
**Sponsors:** National Abandoned Infants Assistance Resource Center, National Center for Substance Abuse and Child Welfare

For more information, go to [http://aia.berkeley.edu/training/SEN2010](http://aia.berkeley.edu/training/SEN2010) or contact Amy Price at amyprice@berkeley.edu or 510-643-8383.