



Mothers on the margins: Implications for eradicating perinatal HIV

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Abstract

Tactics aimed at reducing perinatal transmission of HIV are proving ineffective at accomplishing complete eradication: a group of women with HIV remain at very high risk for transmitting the virus to their newborns. This study engaged a uniquely high-risk group of HIV-infected mothers as expert informants on childbearing with HIV to inform strategies to eradicate perinatal HIV transmission.

The sample draws from an Illinois Department of Children and Family Services (DCFS) database of 1104 HIV-seropositive women with children in protective services between 1989 and 2001. Of these, 32 women knew their HIV-positive status and gave birth to at least two children after 1997 (zidovudine widely implemented as standard of care). Twelve were accessible and consented to participate. Three others, currently pregnant, also participated. Fifteen interviews were completed.

The 15 women had given birth to 78 children (9 HIV-infected), fathered by 62 men. Respondents were severely socioeconomically marginalized. They were aware of their HIV status and the benefits of prophylaxis, most desired healthy babies to parent, and most delivered their babies in hospitals equipped to provide adequate prophylaxis. Yet most received inadequate or no prenatal care and did not disclose their HIV status at delivery. Women indicated that denial and substance use were the primary intrinsic barriers and disrespectful treatment was the primary extrinsic barrier to disclosure and care. Women's recommendations about eradication of perinatal HIV transmission emphasized the problem of substance use, the need for private and thorough communication with medical and DCFS personnel, and the need for positive social relationships to enable HIV positive mothers to engage in care. Attention to potent social and institutional barriers that impair the ability of the most marginalized women to disclose their HIV status and accept care is essential to realize eradication of perinatal transmission.

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Keywords: Perinatal HIV transmission; Marginalized women; USA

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Introduction

Once you tell them, it just starts showing up everywhere. Some women go to different hospitals and don't disclose anywhere to avoid detection. (R₈; G₄P₃)

The success of biomedical and public health efforts to eradicate mother-to-infant transmission of human immunodeficiency virus (HIV) in the United States is evident in the remarkable ten-fold reduction in such cases since the introduction of zidovudine (ZDV) only a decade ago, to a national average of 2–4% (Lallemant et al., 2000; Mofenson, 2003). Because of advancements in treatment of HIV with highly active antiretroviral therapies (HAART), HIV-infected individuals are living longer and healthier and, therefore, may have greater desire and opportunity to reproduce. In the year 2000, 6000–7000 reproductive-age women with HIV gave birth to approximately 280–370 children (Office of Inspector General, 2002).

Prior research indicates that women with HIV share similar feelings with HIV-negative women about the desire for pregnancy and motherhood, as well as autonomy on decisions relating to contraception and sterilization (Bedimo, Bessinger, & Kissinger, 1998; Ingram & Hutchinson, 2000; Pivnick, 1994; Williams, Watkins, & Risby, 1996). Most pregnant women with HIV avail themselves of appropriate prenatal and HIV care so as to minimize the risk of virus transmission to their newborn (Silverman, Rohner, & Turner, 1997). Pregnancy outcomes of HIV-infected women who receive perinatal HIV treatment demonstrate a transmission rate below 2% (Mofenson, 2003).

Advances in the availability of antiretroviral pharmacotherapy and basic scientific knowledge about HIV, coupled with public health campaigns, have been so successful in achieving reduction of perinatal transmission in the US that the focus has now shifted to the goal of eradication (Mofenson, 1999). Effective reduction strategies include public education campaigns to increase prenatal care rates, promotion of prenatal and intrapartum HIV counseling and testing, and adherence to recommended treatment regimens in pregnancy (Bulterys & Fowler, 2000; McCormick, Davidson, & Stoto, 1999). However, the tools that have proven so effective at reducing perinatal transmission of HIV are proving inadequate for accomplishing eradication. While the annual number of new cases in the US is small, the incidence is steady. If full eradication of perinatal transmission of HIV is to be achieved in this country, new strategies are needed.

We consulted HIV positive mothers known to have given birth after little or no prenatal care but with knowledge of their serostatus, in order to seek their views on perinatal transmission. Specifically, we elicited

(1) their motivations for childbearing, (2) their experiences with the health care and child welfare systems, and (3) their perspectives on possible strategies to prevent perinatal HIV transmission.

Methods

This study used qualitative methodology to better understand how to eradicate perinatal transmission of HIV. First, interviews were conducted with key stakeholders representing the public health and child welfare systems, medicine, advocacy groups, and mothers with HIV. These interviews, and a thorough review of the literature relating to HIV and childbearing, informed cohort selection, elaboration of the theoretical approach, and articulation of the major domains of inquiry.

To identify HIV-seropositive mothers most similar to those known to give birth to HIV-infected neonates in Illinois, we accessed our sample from an Illinois Department of Children and Family Services (DCFS) database that included 1104 HIV-seropositive women with children in protective services between 1989 and 2001. To further identify mothers at high risk for perinatal transmission and who might not have been reached by current prevention strategies, we included only those who gave birth after 1997 (ZDV widely implemented as standard of care), with knowledge of their HIV seropositivity, to at least two children. (Table 1)

Applying these criteria, we identified 32 eligible mothers and located 14. Twelve of these women agreed to participate in a 2 hour interview and were provided transportation and/or transportation reimbursement and \$25 in consideration of their time. Three additional mothers meeting the same characteristics, but currently pregnant, were also recruited from the clinical setting and enrolled.

A proxy interviewer was used to enhance protection of the respondents' confidentiality, as members of the investigator team could potentially identify or care for respondents in the clinical or child welfare setting. Upon enrollment, respondents were given the option of using a pseudonym for the interview. Neither interviewer personnel nor investigators knew the respondent's identity. Each of the mothers participated in a 60–120 minute, face-to-face, semi-structured interview under conditions of strict privacy. Consent was obtained, including separate consent for audiotaping, with no refusals. Four institutional review boards granted human subjects protection approval.

Development of the domains of inquiry and the nature of questions in the interview guide was derived from a feminist theoretical perspective. This perspective posits respondents as expert informants on their own life

Table 1
Particulars of sample

Ethnicity	
African American	14/15
Other	1/15
Median age (yrs)	28 (20–40)
Monthly income All sources (US \$)	
<100	4/12
100–499	2/12
500–1000	5/12
>1000	1/12
Ever formally employed	5/13
Children (mean, range)	5.1 (2–12)
Routine prenatal care	3/15
Number of mothers giving birth to HIV- infected child	5/15
Number of HIV-infected children born to mothers in our sample	9 ^a

^aOne mother had 3 infected children, 2 mothers had 2, 2 mothers had 1 infected child each.

experiences, thoughts, attitudes, and expectations and allows investigation of the phenomena as experienced by the women themselves. Three main topic areas were explored with key probe questions; key words led to specific follow-up questions. In addition to demographics, childhood experiences and living environment, the three topic areas of inquiry included: (1) motivations, behaviors and attitudes regarding contraception, pregnancy and childbearing; (2) experiences with the health care and child welfare systems; (3) ideas regarding strategies for eradication of perinatal transmission of HIV.

In order to identify individual respondents' quotations in the results, each has been assigned a randomly generated respondent number listed as "Rx." Gravidity and parity are notated as G the total number of pregnancies, and P, the total number of live births. Due to the uniqueness of this sample, care was taken to further de-identify individuals by assigning variation to the respondents' reported parity. This was accomplished by randomly adjusting each respondents' parity by adding an integer between -1 and +1. This maintains individual-level context while maximizing respondent anonymity. The results section conveys respondents' words using direct quotations (" "), paraphrase (' ') and summarization (not punctuated). Direct quotation was not always possible due to privacy concerns and technical limitations of audiotaping.

Using the grounded theoretical approach, the interviews were analyzed by all members of the interdisci-

plinary research team for the emergence of common themes using a modification of the Bogdan/Bilken Qualitative Coding and Accounting Scheme. Open coding and investigator and theory triangulation were used as validation techniques to achieve theme saturation. Sequential and iterative interim analyses were conducted after interviews 4, 8, 12 and 15. The final results were shared with informed experts in order to establish external validity.

Results

Demographics, childhood and social environment

I began drinking when I was 8. My mother beat me and I was taken by DCFS. I became sexually active when I was 10. I was forced to do it, but then I went along with it. It was my dad. He started abusing me after DCFS took me away and I came back for visits. Both my parents had problems with alcohol. (R3; G5P3)

I lived with my mother who was in the street a lot. She died when I was 4 and we continued to live with our grandmother. She told us nothing about menstruation and sex. When my older sister had her first period...my grandmother cussed her out and told her she must have been out in the street fooling around...so my grandmother put her out on the street...She did the same thing to me when I got my first period when I was 11. (R15; G12P12)

I was an only child and lived with my mom. Her boyfriends started molesting me sexually when I was 8. I told my mother...but they were beating her, so it wasn't really something she could control. I got tired of it and started to run away at age 10, dropped out of school, and started to do drugs and have sex when I was 12. I got pregnant when I was 12. (R7; G5P4)

The 15 respondents were predominantly young, African American, undereducated, unemployed, single, and living well below the US poverty line. As summarized in Fig. 1, common life circumstances included abuse as a child, substance use including alcohol and drug dependency, physical/sexual/emotional abuse as an adult, transience and homelessness and trading sex for money, shelter, and/or drugs. All of the women shared at least two of these circumstances. Nearly every woman stated she had no friends, attributed mainly to transience. Substance use linked women to people "who you couldn't call friends." The mean number of children per woman was 5.1. Sixty-two men fathered the 78 children born to these 15 women. Twelve of the 15 women were single. Each of the women interviewed experienced her first pregnancy as a

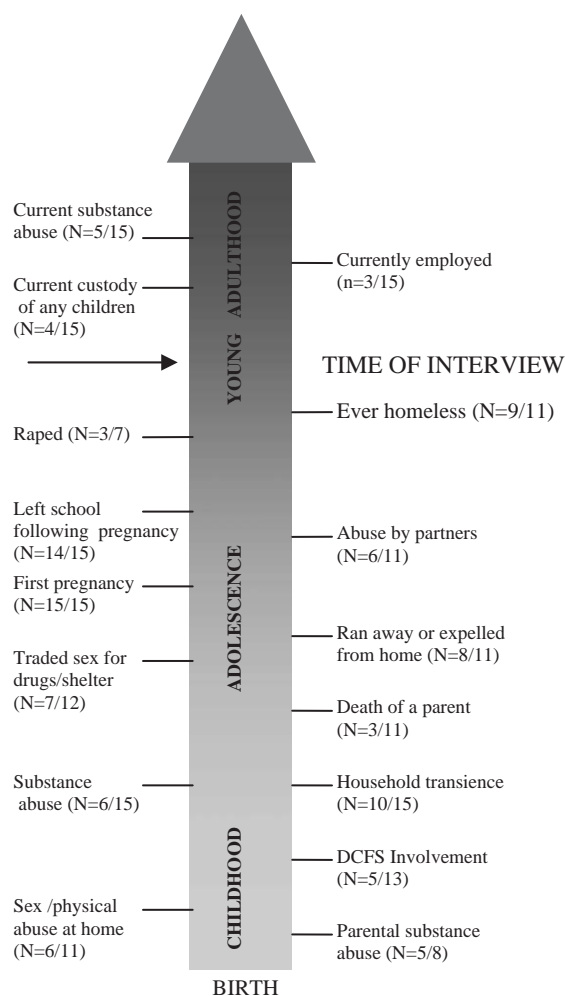


Fig. 1. Composite life event history (*n*/# respondents of whom question was asked). This figure provides simplified summary data derived from the collective experience of the respondents. Many such events occurred on more than one occasion and conditions, such as substance use and transience, occurred over time.

teenager. This marked a sentinel event that, in all but one case, coincided with dropping out of school, and in the majority of cases, also resulted in enduring disconnection from home.

Few reported routine prenatal care and none reported routine contraceptive or condom use. A highly prevalent theme of “not planning, not preventing” arose with regard to questions about women’s intentions toward future childbearing and barrier protection to prevent spread or acquisition of sexually transmitted infections, including HIV. In her interview notes, the proxy interviewer describes R₁₂; G₁₂P₁₁: “She did not mean to get pregnant the last two times, but then again she wasn’t trying NOT to get pregnant either. She didn’t really think about it... Her partner never raised the issue

either—they never talked about whether they wanted more kids or having more kids. It was not something she thought about.”

Motivations for childbearing

All of the women in this study expressed a strong desire to be a parent. Several themes emerged to explain the study respondents’ motivations for childbearing, including (1) replacing children who had been removed from custody; (2) demonstrating capacity to be a good parent; and (3) filling an emotional void.

Many women explained their motivations for childbearing as a desire to replace children who had been removed from their custody. All but two women had at least one child removed from custody. More than two-thirds of the respondents were not currently living with any of their children. Respondents expressed uniformly strong reactions to losing custody of their children and to living apart from them.

Even though it seems so perverse, each time I had a baby, it was taken away. So every time I wanted another one because I wanted to be able to take care of my own child. (R₅; G₈P₆)

If I had been able to get my kids back and raise them myself, I never would have had more kids. (R₁₀; G₇P₆)

Women also described their desire to correct past parenting mistakes as a powerful motivator for childbearing. For example, R₁₀ commented that she felt a strong need not just to parent, but to “do it right.” Another woman stated: “I wanted God to give me another chance...to take care of a child and have a bond...a chance to raise a child.” (R₂; G₂P₁, currently pregnant).

Most of the women perceived that motherhood could fill an emotional void resulting from experiences of abuse, neglect, frequent transience and homelessness. Repeatedly, women spoke of “chaotic” and “unstable” conditions originating in early childhood, and nearly all of the women stated that they had never been able to form close friendships: ‘I always remember being depressed as a child. I was always alone and felt as if I never had any stability or any friends or anything I could count on...I moved around so much, it was hard to make friends.’ (R₆; G₄P₃) Relationships with spouses or partners were equally unlikely to provide a source of social support. Only three women were currently living with their partners, and only one described any partner as a consistent source of love and support.

In addition to their few and fragmented personal relationships, women also described institutional isolation. For example, 14 women had dropped out of high school, three were currently employed and just one

identified her work as a source of emotional or personal satisfaction. Although several described themselves as spiritual, few of the women reported feeling connected to a religious community or institution. While many women encountered substance abuse, mental health and HIV treatment programs, these settings neither facilitated lasting social bonds nor provided reprieve from traumatic home environments. In this context, women repeatedly emphasized that motherhood could fill an emotional void and even provide reason to live despite hopelessness exacerbated by HIV. For example:

It's (pregnancy) probably something that women need to fulfill their lives because there's nothing else to fulfill their lives. Especially when you are positive you try to find a person, a thing or a drug to fulfill your life. And you think some of the time when you have a baby and the baby will bring fulfillment that you never had in your life. (R2; G2P1)

My kids are what make me want to live and be strong. If I didn't have kids, I wouldn't be motivated to put up with all the HIV stuff. (R8; G4P3)

When you are HIV positive, you don't know what is going to happen during pregnancy. But you have this child that you can raise, love, nurture, teach and you can give some stability to. Most women will count that as a blessing. (R2; G2P1)

One woman described childbearing as a way to fight, or take control of HIV, saying that women with HIV have children because:

They are not letting HIV control them. You can't let it control your life, or you will go down. If you are depressed and have no hope, if you are letting the HIV get to you and control you, you won't last long. But if you are in control and realize you are still beautiful, then you will live longer. And you have to live longer for the kids even if not for yourself. (R8; G4P3)

Another talked about childbearing as a way to hide her HIV infection: "If I didn't have the baby, people would wonder why and what was wrong. I was trying to prove to people I wasn't what I really was." (R7; G5P4)

Women's interactions with the health care and child welfare system

Although most of the respondents recognized value in prenatal care as valuable for a healthy infant, ten women reported no or extremely intermittent prenatal care for any pregnancy, and four reported limited and late-onset care for at least one pregnancy. Only one woman stated that she had received continuous prenatal care for each of her pregnancies. Most women experienced most of

their deliveries alone at hospitals where they were unknown. Although one woman reported having had some support from her family during her pregnancy, she delivered at the baby's father's house while he lay nearby, too intoxicated to be aroused. "I didn't cut the umbilical cord or touch anything...I made sure all the gunk was out of my daughter's mouth and wrapped her up real good...there was no phone in the house...so I just had to do it by myself." (R2; G2P1).

Generally, respondents did not attribute lack of care to logistical barriers (e.g. lack of transportation, insurance, or childcare). Instead, they emphasized a personal history of negative and dehumanizing interactions with both the health and child welfare systems and posed these as important reasons for not availing themselves of HIV or other medical care or social services during, or outside of, pregnancy.

Two common themes summarize the women's perceptions of their experiences with the medical and child welfare systems: disrespect and lack of regard for privacy and confidentiality. Disrespect included infantilization, judgmentalism, and reluctance to provide care for or believe HIV-infected individuals. In the course of medical care, several women reported being "talked down to" or "treated like a child" by physicians or other staff. Others complained about the "sorts of looks" or tone of voice that doctors used to convey moral disapproval:

Women are afraid...of having people yell at you that you shouldn't have gotten pregnant and that they should be ashamed for being pregnant when they are HIV-positive. (R6; G4P3; intermittent prenatal care)

One woman stated that in order to disclose her status to physicians, she would need to feel "comfortable with them and certain they wouldn't look at me that way—you know, judging me. I don't like the way they look at you and judge you." (R10; G7P6; no prenatal care)

Poor care was attributed to providers' insensitivity to HIV-infected individuals. Two respondents gave detailed descriptions of experiences seeking medical care where complaints were "not taken seriously" (R8; G4P3; limited prenatal care) and where doctors and nurses refused to touch them or perform physical examinations. One woman painfully recalled being transferred from one hospital to another with an extensive, blinding eye infection:

I went to see the doctor at (the) hospital and told them that I was HIV positive. So of course no one wanted to have anything to do with me then...and they transferred me from there...nobody even wanted to touch me... I was taken by taxi to another hospital...and had emergency surgery and had to stay in the hospital for 34 days. (R15; G12P12; no prenatal care)

Nearly all of the women recounted experiences where medical and social service personnel displayed lack of regard for privacy and confidentiality. These breaches evoked resistance to utilization of health services and, when care was accessed, inhibited disclosure of HIV status.

Despair about having a newborn removed from custody also impeded participation in prenatal care and disclosure of HIV status; women perceived that engagement of health providers would trigger DCFS notification, and/or that disclosure of a new pregnancy to DCFS would guarantee removal of the newborn. This commonly resulted in presentation for care in active labor and/or anonymous delivery at an institution where neither identity nor medical history were known: “Once you tell them, it just starts showing up everywhere. Some women go to different hospitals and don’t disclose anywhere to avoid detection.” (R₈; G₄P₃; limited prenatal care).

Women perceived violations of their confidentiality to occur upon initial diagnosis and during treatment, both within the medical institution and in the course of information-sharing between institutions. These stigmatizing experiences caused women to distrust medical and social service personnel, particularly with disclosure of their HIV status. For example, following a gang rape, one woman described receiving a phone call from a private clinic asking her to come in for test results:

When I went in, the receptionist was sitting in one of those windows that faces the waiting room and told me (I was HIV positive). Nobody asked me into a private room or anything and I just ran out of there. There was not a doctor or nurse or counselor, just the receptionist telling me. I went on a crack-smoking binge...nobody ever tried to contact me about it again. (R₇; G₅P₄; intermittent prenatal care)

Many women directly attributed avoidance of HIV treatment and prenatal care, as well as nondisclosure of their HIV status to physicians and counselors, to these violations. One woman rescinded from a drug treatment program after a trusted counselor disclosed her HIV status in the presence of another client. In another case, a woman asserted that DCFS caseworkers and hospital staff needed to better protect patients’ privacy:

A person who is positive should have control over who they decide to tell and who not...Other people seemed to just know. Medical staff would just talk about it right in front of me at the hospital and with other staff around. (R₈; G₄P₃; limited prenatal care)

Privacy concerns, as an extrinsic barrier to care, prevented women from accessing HIV-related information, even in anonymous public spaces. Twelve respon-

dents reported that informational materials such as brochures and pamphlets could not be accessed due to concerns about being observed obtaining or possessing these items. R₈ specifically mentioned that she “would never pick up anything that said HIV on it” and would leave behind or rid of materials such as informed consent documents, medication information or support hotlines because “somebody could see those things and read between the lines” to learn her HIV status. In addition, she routinely “peeled the labels off the pill bottles” to avoid discovery.

Additionally, two important intrinsic factors, substance use and individual denial of HIV status, emerged as interrelated and complicating factors for engaging in care. More than two-thirds of the women reported current or former drug use, often beginning around puberty in response to traumatic events, such as expulsion from the home, loss of a parent, and/or sexual, physical and emotional abuse (Fig. 1). All of the women with a drug use history described obtaining and using drugs as a priority over prenatal care, childcare, and HIV self-care, as illustrated further below. In these instances, denial of HIV allowed and/or reactivated women’s substance use, and substance use facilitated denial of HIV infection. For example, one woman related that drugs allowed her and her partner to ‘ignore the effects’ that both HIV and drug use could have on their own or the fetus’ health (R₁₀; G₇P₆; no prenatal care).

Denial of HIV infection surfaced as a common theme, even among non-substance users, and exacerbated other barriers to care. Two-thirds of the women explicitly identified denial or fear as a barrier to receiving perinatal HIV treatment: “They stay away from treatment as long as possible because they are scared of what it will be like and they figure they are going to die anyway.” (R₆; G₄P₃; intermittent prenatal care) More than half described being “in a daze” for prolonged periods characterized by unwillingness to engage in any activity that reminded them of their HIV status. Denial also inhibited women from disclosing their diagnosis to others, including sexual partners and physicians. One woman who accepted her HIV infection commented on the meaning of emerging from denial and finally seeking care:

When you first find out you are positive, you go through a state of denial and depression. You get mad. You tell the doctor you are not HIV positive. I went through it [denial] for about 3 months. After that I just said, fuck it, I’m positive, I just have to live with it. Once I learned there were these different medications and I started taking the medications I realized it wasn’t no death wish. Shoot, might as well call it my best friend. (R₂; G₂P₁; limited prenatal care)

Respondent suggestions on possible strategies to prevent perinatal HIV transmission

Respondents were asked about factors that facilitated or hindered a woman's engagement in prenatal care. Many women shared the belief that no intervention could be successful for women using drugs:

Mothers on drugs—if they like getting high and just don't care, there is nothing you can do. But if they are addicted but really want to stop, then you can help. The mother has to want to quit. (R₆; G₄P₃; intermittent prenatal care)

They were also asked to comment on how medical personnel could successfully intervene to eradicate perinatal transmission. Respondents advocated for: (1) thorough information about treatment with emphasis on benefits to the baby and (2) social support. All of the women who participated in this study expressed awareness that HIV could be perinatally transmitted, and that medication could be used to prevent HIV transmission. However, skepticism about treatment derived from a widely held perception that public health messages and providers provided superficial and overly simplistic information.

As much as you see about HIV on the billboards and buses and everywhere, women should know what HIV does to your immune system. And if it hurts your immune system, you know what it's going to do to the baby. So they should already know what's going to happen if they don't get immediate help. (R₂; G₂P₁; limited prenatal care)

Women specifically suggested that doctors should not assume mothers to be ignorant, and focus on giving them more detailed information about HIV disease, risks and benefits of treatment and the meaning of blood tests.

Doctors can't just tell mothers to take this medication or that medication, they have to explain what it does and what the risks are. ... [Doctors should] show the patient the reports—here is your t-cell count before and here it is now that you have started this medication. Because you have to see that it really is working and not just take their word for it. Otherwise, if you feel about the same and are pretty well, it doesn't seem like the drugs are making any difference and you don't feel motivated to take them. They have to show you what is going on inside of you that you can't see—how the drugs are helping you and your baby. (R₈; G₄P₃; limited prenatal care)

Nobody is going to take a chance on some medication they don't know anything about... You would have to give me a piece of paper that told me

about the drug and the side effects... I would have to read it myself and see that it said it was supposed to do everything you were telling me it was supposed to do. I'm not going to just believe what you say. (R₂; G₂P₁; currently receiving prenatal care)

Doctors “never said a word about what the drugs did or how they worked or even about any side effects. If they had explained about what the drugs did, I might have agreed to them.” (R₄; G₆P₆ no prenatal care)

Others suggested that women would be more willing to adhere to care and take HIV drugs if they knew that they were for their baby's health, although there was not consensus on whether these messages should be gain- or loss-framed:

Women with HIV who are pregnant need to hear that women who are HIV-positive can have a negative baby. Women need to hear this and they need to hear it from somebody who knows. They have to know it isn't all-hopeless and that you can have a normal baby. (R₆; G₄P₃; no prenatal care)

Tell them they are killing their babies if they don't get care, don't get (HIV) drugs. You have to appeal to how they care about their babies. (R₃; G₅P₃; regular prenatal care)

In addition to more thorough and honest information, women emphasized a critical need for persistent, caring, “helpers” who would maintain contact with them from diagnosis, through denial and treatment, and assist them in negotiating prenatal care, HIV treatment, and even custody issues. Although virtually none of the women could identify any lasting friends, six described pivotal individuals who were persistent and compassionate, even in the face of repeated failure. When asked if anything could have been done to help her participate in prenatal care, one woman responded:

Yes, if there could have been somebody who was more persistent in wanting to talk to me, that would have helped a lot... One time only, did they ask if I wanted to come to a group and I just said I'd think about it. But if they had come back and been more persistent about it—if I could have been part of a peer group of other people like me to talk about things with, I probably would have been healthier and would have thought about these issues. (R₁₅; G₁₂P₁₂; no prenatal care)

In addition to persistence, women felt that compassion may motivate acceptance of care. One woman reported that she was “afraid and ashamed” after finding out her HIV status. She explained that, “If somebody who already knew my HIV status had come to me and told me I was still OK as a person and had gone with me to get therapy I might have been more

willing to get medical treatment” (R₄; G₆P₆; no prenatal care).

As respondents generated ideas about how to best intervene with other women to eradicate perinatal transmission, a few shared positive experiences about key “helpers” whom they had encountered. Some responded best to helpers who offered compassion by combining professional services with personalized care. For example, one woman noted that she had a good, close relationship with her case manager for several years prior to HIV infection. They had become friendly and would go to church together or out to breakfast. This relationship provided solidarity and instrumental support at the time of HIV diagnosis that eased the burden of the bad news. According to this respondent, “hearing the news wasn’t as bad” because it had happened in a supportive environment and they immediately got her “hooked up with the clinic where they had special prenatal care for mothers with HIV, as well as into other support groups” (R₁₃; G₄R₄; limited prenatal care).

In another case, a woman described a caseworker whose compassion influenced her adherence to HIV treatment. She described how he was sensitive to her difficulty balancing work and her medication regime. He would come to her work “just like a regular customer, get the car keys, and then when he came back, the medicines were waiting for me in the trunk.” She continued, “He was great. He would call me up just to say hi or come by my house to see how I was doing. When I switched cocktails, he would make me come in every day so he could watch me taking my meds.” She concluded that his attention made her feel “loved,” and that “people with this disease need to know that, need to know people care about you” (R₇; G₅P₄; no prenatal care). R₁₅ commented that “instead of somebody official all the time,” she really wanted to connect with someone who she “could have talked to, who would have been concerned about her.”

Women felt strongly that support programs should engage peer counselors who previously had experience with drugs, and/or who were HIV infected. For example, R₇ commented that if her counselors hadn’t been former addicts they would not have earned her trust.

If you ain’t never walked in my shoes, why should I listen to you? I wouldn’t want a counselor who hadn’t been down the same road I’ve been down... Just knowing somebody else had been there would have helped a lot. It’s easy for somebody who isn’t infested (sic) to tell you how to live your life. But you need to hear it from a counselor who is HIV positive, who can understand what you have been going through. These women need somebody who can feel what they are feeling.

Another woman stressed the importance of being part of support groups where there were people “going through the same things as you.” She remembered,

sitting in the waiting room looking at all these people and all these thoughts were going through my head because I didn’t know it was a place for just HIV. I’m looking and I’m wondering and this lady came up to me, and she has been my friend ever since, and she said, ‘It’s not as bad as you think it is.’ I’m looking at her like you don’t know what my problem is. She looked at me and said ‘I have the same thing you’ve got and do I look like I’m dying?’ She was all nicely groomed and nicely dressed and she was going around smiling at everyone. And I said, ‘You don’t know what I got.’ And she said, ‘You got the virus, everybody here got the virus, that’s why we’re here.’ It is really important to get that personal interaction with other people in the same boat with you. (R₁₃; G₈P₆; limited prenatal care)

Discussion

The women’s narratives repeatedly returned to the theme of severe social deprivation to describe the prevailing context in which they acted with ambivalence, hopelessness or denial regarding HIV and prenatal treatment. Their suggestions about eradication of perinatal HIV transmission focused on strategies to improve or implement positive social relationships that would enable communication with and engagement of HIV positive mothers like themselves.

Social status, social support, and embeddedness of individuals in a social network have been shown by social scientists to significantly influence health status and disease outcomes (Berkman, 1995; House, Landis, & Umberson, 1988). George Engel’s biopsychosocial model, described in 1977, built on social systems theory to posit psychosocial etiologies as the root cause of disease (Engel, 1977). Extending Engel’s work, the interactive biopsychosocial model (IBM) provides a framework for understanding both social causes and consequences of illness and how these interact to influence health (Lindau, Laumann, Levinson, & Waite, 2003). Additionally, the IBM describes health as a joint product of an individual’s health and the health of a significant social other (e.g. a spouse or partner, parent, or even community) and interventions to promote health or treat disease would explicitly consider the resources of the other.

In the context of HIV disease, social support has been shown to influence access to, acceptance of, and adherence to therapy as well as survival (Burgoyne, 2004; Cohen, 2001; Cox, 2002; Crosby et al., 2001; Gielen, McDonnell, Wu, O’Campo, & Faden, 2001;

Shelton et al., 1993). Stigma and shame associated with HIV disease in the United States, particularly for pregnant women, continues to create a formidable societal barrier to care (Black & Miles, 2002; Fife & Wright, 2000; Goldin, 1994; Herek, 1999; Oliva, Rienks, & McDermid, 1999; Parker & Aggleton, 2003). Social status and support have been shown to mitigate these effects in particular (Catz, Gore-Felton, & McClure, 2002; Ciambone, 2002; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003) and are associated with better quality of life and health in people with HIV (Burgoyne, 2004; Cox, 2002; Gielen et al., 2001; Gregson, 2004).

Despite disparities in social resources among women with HIV in the US, the majority of pregnant women with HIV are generally able to mobilize social support and access appropriate care. However, for the women described in this study, family members were singularly abusive or absent, friends were virtually non-existent, and social networks formed and faded around substance use, treatment or trade. Application of the IBM to these findings draws attention to the absolute absence of the social other for many of the women in this study, and to the liabilities posed by the social other in cases where one did exist, such as abusive parents or exploitive partners. The social deprivation and societal disdain experienced by these women, even in the medical and child welfare settings, fed despair and denial, profoundly motivated childbearing, and often represented an insurmountable barrier to pursuing perinatal HIV care despite awareness of its potential benefits.

Descriptions of positive relationships with child welfare system caseworkers and health care providers were complicated by power differentials and the monitoring role required of these providers, thereby reactivating, for many women, past experiences of betrayal. This dynamic has been recognized in the social policy and economics literature as a principal-agent problem where providers (agents) are beholden to multiple entities (principals) with potentially conflicting interests and exploitation of shared information frequently occurs (Arrow, 1985). In the context of these powerful relationships, women's experiences with disclosure of sensitive personal information, including HIV, pregnancy status, and substance use, frequently involved loss: loss of privacy and confidentiality, loss of children, loss of a capacity to trust. Ensuing distrust in social welfare and medical institutions frequently evoked denial, anger, and relapse. Non-disclosure of HIV status at junctures where care could have been instituted could, in varying cases, be interpreted as a woman's effort to protect her privacy, to establish control, as an act of retaliation or as passivity in the setting of intoxication; in any scenario, unwillingness to disclose emerged as a potent barrier to receiving perinatal HIV care.

In contrast to prior work (Mikhail, 1999; Oliva et al., 1999; Pivnick, 1994; Silverman et al., 1997; Walter et al.,

2001), this study reveals that transmission of HIV in a very high risk group of pregnant women is not due to lack of knowledge about HIV or transmission, and not primarily due to logistical or economic access issues. All of the women interviewed acknowledged awareness of perinatal transmission and the role of antiretrovirals in preventing transmission. Women largely knew how and where to get care and expressed that logistics were not prohibitive. Instead, women's ability to avail themselves of appropriate therapy was limited by the environment of care. Many women felt that poor treatment emanated from providers' judgments about and disdain for substance use and HIV, particularly in the setting of pregnancy.

These findings are corroborated by work in the international context, which has also suggested that difficulties experienced by women during their contacts with health care providers can contribute to their non-participation in prophylaxis and prenatal care (Msellati et al., 2001; Painter et al., 2004). For example, one study conducted in an antenatal clinic in Abidjan, Cote d'Ivoire found that most of the women explained their non participation in follow-up visits to the clinic by referring to negative experiences they had while interacting with program staff (Painter et al., 2004). As in our own study, women viewed an explicitly positive demeanor among staff members, as well as clear explanations of the medical procedures, as essential to their willingness to continue treatment.

The ideas and experiences of the women in this study, as well as those in international contexts, compel us to reconsider the limitations of our interventions to achieve eradication of perinatal transmission in the current climate. Our analysis elucidates the mechanisms that link severe social marginalization to medical decision-making and behaviors that result in perinatal transmission of HIV, and prompts new thinking about how to reach the women who have not yet been reached by traditional prevention models. Rather than focusing primarily on information campaigns about HIV transmission and treatment, or the logistics of getting to health care appointments, our findings suggest that what may also be needed is attention to the social environment in which women disclose their HIV status and receive medical treatment. Women who are at the margins of society, and who lack coherent and supportive social networks, may be reluctant to disclose their HIV-status and to seek treatment until they can be confident that the actors in these environments will first, do no harm.

Study respondents' own suggestions about socially oriented interventions help to confirm this interpretation. For example, the women consistently highlighted the importance of the social qualities of caregivers, stressing the need for more persistent, compassionate care and peer counselors who were "going through the

same things as you,” to act as supporters. And women stated they wanted increased, honest and explicit dialogue with medical and social service personnel toward establishing realistic expectations about confidentiality, removal of children and reunification, and consequences of non-adherence. All of these suggestions point to the need to focus on the social environment in which care is provided to promote and ensure acceptance of interventions that have the capability of achieving eradication.

Conclusion

In spite of highly efficacious medical and public health interventions for preventing mother-to-child transmission of HIV in the United States, some HIV seropositive mothers continue to expose and infect their newborns at birth. All of the women we interviewed knew of their HIV status prior to giving birth, desired healthy babies, and most delivered their babies in hospitals equipped to provide adequate prophylaxis. Social marginalization, experiences of disrespectful and abusive treatment, denial, substance use, and loss of previous children to the child welfare system appear to stand firmly in the way of these mothers' willingness to disclose their status to health professionals. Without disclosure, the most efficacious interventions are rendered powerless.

In contrast to prior work in this area, this study gives voice to a group of women who are represented statistically by the small, but plateauing number of perinatal transmission cases, and whose stories and ideas have not yet been heard. In a quest for eradication, where any single case of mother-to-child transmission must be considered a failure, biomedicine and public health may need to re-examine the environment of caring for very vulnerable mothers.

Comparisons with research conducted in international settings suggest that the lessons imparted from these mothers, particularly about reforming institutions and the importance of social advocacy and support in accessing care, may apply to similarly disenfranchised mothers not affected by HIV and to HIV-infected mothers living outside of the United States, in areas where biomedical resources are scarce and perinatal transmission rates remain staggeringly high (Painter et al., 2004).

Acknowledgements

The authors would like to acknowledge Martha Van Haitsma, Ph.D. Dr. Van Haitsma served as the proxy interviewer for this research. The Pediatric AIDS Chicago Prevention Initiative and the Robert Wood Johnson Foundation Clinical Scholars Program pro-

vided funding for this work; AIDS Legal Council of Chicago provided in-kind support of one of the authors. Ellen King provided graphic and bibliographic assistance.

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