ELSEVIER

Social Science & Medicine 62 (2006) 59–69

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

Mothers on the margins: Implications for eradicating perinatal HIV

Stacy Tessler Lindau[a,*], Jessica Jerome[b], Kate Miller[c], Elizabeth Monk[d], Patricia Garcia[e], Mardge Cohen[f]

[a]*Departments of Obstetrics & Gynecology and Medicine, University of Chicago, MC 2050, Chicago, IL 60637, USA*
[b]*MacLean Center for Clinical Medical Ethics, University of Chicago, Chicago, IL, USA*
[c]*AIDS Legal Council of Chicago, Chicago, IL, USA*
[d]*Illinois Department of Children and Family Services, IL, USA*
[e]*Department of Obstetrics & Gynecology, Northwestern University, USA*
[f]*Rush Medical College and Cook County Hospital, Chicago, IL, USA*

Available online 29 June 2005

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.

Keywords: Perinatal HIV transmission; Marginalized women; USA

*Corresponding author
E-mail address: slindau@babies.bsd.uchicago.edu (S.T. Lindau).

0277-9536/$ - see front matter © 2005 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2005.05.012

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. (R_8; G_4P_3)

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