Published in final edited form as:

AIDS Care. 2012 April ; 24(4): 491–495. doi:10.1080/09540121.2011.613906.

Brazilian Mothers with HIV: Experiences with Diagnosis and Treatment in a Human Rights Based Health Care System

Jessica Jerome¹, Marli Teresinha Gimeniz Galvao², and Stacy Tessler Lindau³

¹St. John's College, Santa Fe, New Mexico 87505, USA

²Universidade Federal do Ceara, Faculdade de Farmacia Odontologia e Engermagem, Fortaleza, CE 60430-160, BR

³Departments of Obstetrics and Gynecology and Medicine. University of Chicago, MC 2050. Chicago, IL 60637, USA

Abstract

Drawing on in-depth interviews with a group of urban poor HIV positive mothers in Northeastern Brazil, this essay examines their experiences with HIV medical diagnosis and treatment. It argues that strong social and religious networks as well as the Universal HIV treatment program provide Northeastern Brazilian mothers with forms of support that may be absent in other countries. It further suggests that more research be done to determine how particular forms of health care, such as the human rights based approach Brazil has taken to HIV/AIDS, inform patient-provider relationships.

Introduction

Brazil is the national center of the HIV/AIDS epidemic in South America and accounts for 57 percent of all AIDS cases in Latin America and the Caribbean (Berquo, 2005). It is also virtually unique among both developing and developed countries in its publicly funded, rights-based, and internationally lauded HIV/AIDS program. Among some of its more innovative approaches include framing the need for Anti Retrovirals (ARVs) as a human right, and providing free access to HIV treatment (Biehl, 2007). In 1996 the Brazilian Ministry of Health mandated universal HIV testing for all pregnant women and free antiviral drugs for HIV positive women and newborns (Knauth, 2003). These and other policies are seen as responsible for a 70 percent reduction in both AIDS mortality and the use of AIDS-related hospital services (MS, 2002). The perinatal transmission rate of HIV has fallen to less than 5%, making it comparable with the U.S. rate (Kreitchmann, 2004; Mofenson, 2003).

Despite the success of Brazil's National AIDS program, its achievements have not been uniform throughout the country (Boletim Epidemiologico, 2010). In poorer regions of Brazil, such as the Northeast, problems concerning education, access to treatment and adherence to medical treatment persist. With regard to perinatal transmission of HIV, economically marginalized women have been shown to be less likely than wealthier women to avail themselves of prenatal care, disclose their HIV status, and consistently adhere to treatment protocols (Goldani, 2003; Miranda, 2005; Ramos, 2002; Kreitchmann, 2004; Lindau et. al, 2006). Our study sought to understand the experiences of relatively poor HIV positive women with HIV diagnosis and treatment in order to elucidate the factors that appear to encourage women to accept care prior to and following their diagnosis.

The study was based in Fortaleza, a large urban center in Northeastern Brazil, which had adopted the national standards of HIV care by the early 2000s, and maintained a large

infectious disease hospital that devoted an entire wing to HIV treatment and care, including the care of mothers with HIV. In spite of these advances, a recent study of five Brazilian cities ranked Fortaleza second in number of pregnant women with HIV (.9%) (Maia, 2008).

Methods

Building on our 2006 work with similar women living in Chicago (Lindau et. al.), this study used qualitative interviews and data analysis techniques with a group of 18 HIV positive mothers from Fortaleza in order to elucidate responses to three main topic domains: HIV testing, revealing HIV status and forms of support used in coping with HIV diagnosis. Initial interviews were conducted with public health workers, advocacy groups, non-governmental organizations and mothers with HIV. These interviews, in addition to a review of the literature on perinatal HIV transmission in Brazil, informed the theoretical framework and the interview instrument. We also conducted participant observation in several homes where women with HIV were living in order to assess the consistency of women's perceptions outside of the formal interview setting.

In order to identify HIV positive mothers most similar to those known to have given birth to HIV positive children in Fortaleza, the HIV positive mothers in our study were all identified through the sole public hospital for infectious diseases in the state. The selection criteria included all women between the ages of 18 and 45 years, who had given birth to at least one child with knowledge of their HIV status. 18 women were identified, all of whom agreed to participate.

During the summer and fall of 2007, these women gave a 2-hour interview and were provided with transportation and/or transportation reimbursement. A proxy interviewer was used in order to protect the respondents' confidentiality. Respondents were provided with the option of using a pseudonym, and neither the interviewer personnel, nor the researchers knew the respondents' identity. Consent was obtained for both written and audio recording of the interview. Two institutional review boards granted human subjects protection approval for this study, including the University of New Mexico IRB, and the IRB of the Hospital Sao Jose, in Fortaleza.

Following the interviews, the transcripts were analyzed using the grounded theoretical approach, in which themes and categories were identified based on the data. These were then coded and entered into Atlas TI, a data management program. Direct quotes from the women are identified by a randomly generated informant number "X."

Results

Social and Demographic Characteristics

Like the majority of women living with HIV in Fortaleza, the 18 women in our study shared the common life circumstances of coming from one of the peripheral neighborhoods (*favelas*) of Fortaleza, and living in conditions of social and economic marginalization (Table 1). Specifically, the women in our study were relatively young (the median age was 33), had typically left school before graduating from high school, had not experienced consistent employment and generally reported a household income of less than 2 minimum wages per month (the minimum monthly salary in 2007 was approximately 400 Real – or about 240 dollars).

Experiences with HIV Treatment and Care: Diagnosis and Disclosure of HIV Status

A total of 13 out of the 18 women we interviewed received a diagnosis of HIV during their prenatal exam. The remaining women either arrived at a health clinic with illness

complaints, or had watched boyfriends or partners struggle with the disease, and were subsequently tested for HIV. Several women reported instances in which doctors reached out to them to inquire about taking an HIV test. For example, two of the women reported that doctors had sought them out and asked if they would be willing to be tested for HIV after their boyfriends or partners had tested positive for the disease.

Although we did not ask women to comment specifically on the quality of their visits with doctors regarding the HIV test, nearly all of the women in our sample voluntarily described details about these interactions that showed their doctors in a positive light. For example, one woman reported that “I had a fever, and I got the chicken pox. I went to the doctor and when I showed him my arm he said, ‘Oh my child, we’re going to examine you for HIV. You might have this virus, should we make a test?’ And I said okay, because it is better to know.” (R6) The majority of the women used words such as *bonita* (lovely) or *simpatico* (nice) to describe the doctor or medical care giver who performed the HIV test.

Stories of positive interactions with doctors surfaced again when we asked women to describe their feelings and experiences revealing their HIV status. Most of the women in our sample revealed a willingness to tell doctors and other medical professionals about their HIV status, and reported doing so with a measure of tranquility. In total, 13 out of 18 women reported that fear of revealing their HIV status did not act as a barrier to care, while 5 women stated that fear of stigma sometimes prevented them from revealing their HIV status. Several women used the phrase *meu amigo* to describe their doctors, including a woman who said, “Even now the doctor is the person that I trust, I get along very well with him, he’s my doctor, my friend.” (R6)

Coping with an HIV Diagnosis: Depression Following HIV Diagnosis, and Motivation to Accept Treatment

We next asked women how they coped with an HIV diagnosis once they had received it, and what role doctors, medical institutions and family networks played in their ability to accept and continue with treatment routines. When asked, “Who helps take you to meetings with doctors or other hospital visits?” in almost every case, the women provided detailed lists of specific family members who would accompany them to the hospital, who could stay home with their children, and who could come to stay with them on overnight visits. There was not a strict uniformity in terms of which family members played which roles, rather mothers, grandmothers, sisters, partners, in-laws and children were all listed as possible, and often interchangeable, helpers.

In addition, despite the fact that most of these women had left school early (more than half of the women our sample had a 6th grade education or below), and fewer than half of them were employed at the time of our interview, they reported being embedded in multiple social settings that facilitated positive social bonds. For example, almost all of the respondents went to church at least once a week, and a third of them went 3 or more times per week.

A substantial number of the women also identified ways that a medical institution (most often the infectious disease hospital) helped to facilitate their HIV treatment. For example, one woman described always bringing her children with her to her medical consults. She stated, “The doctors never said this was a problem, they’re always welcoming.” (R6) “I even bring my 3 year old,” she continued, “he stays at the *casa de apoio* [non-governmental ‘houses of support’ which provide food and lodging to those in need], when I don’t have someone to stay with him.” Another woman pointed out that in the absence of strong family relations she counted on her medical clinic to provide the necessary support. She stated that, “One time I stayed in the hospital, and they talked to me and paid for my children to stay. It

is a marvelous institution. I can't count on anyone from my family to do this, so I depend on these institutions." (R6)

Although the majority of Fortaleza mothers reported having numerous episodes of depression after learning that they were HIV positive, these women also reported mobilizing social and institutional connections to help cope with their reactions. One woman's response to being told she was HIV positive illustrates this common theme: "I wanted to cry all the time, I didn't have the motivation to do anything, I didn't feel like eating. Finally, someone from my family came to see me, and made sure I was able to get out of bed and start living again." (R4) In total, 17 of 18 women reported more than 3 episodes of depression, followed by repeated attempts to overcome depression through help from religion, family, friends or medical caregivers.

When asked to describe in detail how they coped with their depression, women most often invoked their religious faith. But even in cases where religious faith was mentioned, women spoke of the support they received from their doctors. For example, one woman stated, "When I was diagnosed, I turned to God. The next time I saw my doctor, I asked him about counseling because I knew I could trust him. He told me he was my friend, I had known him from before – he had been my doctor for another pregnancy, and he gave me suggestions of people to see." (R14) In total, nearly half of the women in our sample reported relying on their doctor as a source of emotional support following their HIV diagnosis.

Discussion

In interpreting our results, some limitations must be considered. First, there is the potential for recall bias, given that the data were collected retrospectively, and women's recall can be inaccurate. Second it is possible that some women reported greater rates of satisfaction and greater use of health care workers because they had been identified through and interviewed in one of Fortaleza's main hospitals. Given our small sample size, in addition to these other limitations, the results from our data should not be taken as generalizable or statistically representative. In our small, qualitative study of HIV positive women, we found that despite coming from poor neighborhoods, and experiencing logistical difficulties and complications in arranging to attend prenatal care appointments, the majority of women both routinely received prenatal care and were likely to have received an HIV test during one of their prenatal appointments. Prior research on maternal health in the state of Ceara (of which Fortaleza is the capital) confirms that the vast majority of women (91%) report receiving some prenatal care during pregnancy (Lindsey et. al, 2004). But in conversations about the quality of that care, what stood out for us were the number of respondents who went out of their way to praise their doctors and medical care givers, particularly around the issue of HIV testing. The number of times women characterized their doctors as "warm" or "good" and connected this description to their doctor's decision to reach out to them and ask them about taking an HIV test, was striking.

Many of the women in our study also directly linked a willingness to reveal their HIV status to their doctors' warmth, friendliness and the lack of stigma they felt exposed to. Specifically, women stated that the attitudes of medical professionals made them feel comfortable about their own HIV positive status, and thus more willing to disclose it. These responses contrast starkly with our findings from a similar population in Chicago where women expressed an unwillingness to reveal their HIV status because of the disrespectful, stigmatizing attitudes from medical caregivers (Lindau et. al, 2006).

Why would stigma about being HIV positive be less likely to have been felt by the women in Fortaleza? One possible response to this question may be to point to recent research,

which has suggested that Brazil's human rights approach to the HIV/AIDS crisis has led to a decrease in the stigmatization of AIDS. Studies have noted for example, that both doctors and patients report that access to free treatment has positively transformed the general public attitude toward HIV in Brazil (Biehl, 2007; Cseste, 2001; Galvao, 2005; Okie, 2006)

Linking the reduction of stigma to the implementation of a human rights based social policy supports Richard Parker's plea that research about the stigma surrounding HIV should go beyond describing stigmatizing attitudes and stereotypes, and focus instead on the structural conditions that produce exclusion from social and economic life (Parker, 2003). Our study cannot confirm a causal link between Brazil's rights-based HIV programming and the relatively stigma-free environment that many of the women in our study reported, but it is striking that women consistently reported a willingness to disclose their HIV status because of their doctors' open, non-judgmental attitudes. We suggest that future research pursue this link between the adoption of particular health policies and the reduction of stigma regarding HIV/AIDS.

In addition to describing the importance of doctors' positive attitudes during prenatal care and HIV testing, the women we interviewed also brought up more traditional support systems when discussing their behavior following an HIV diagnosis. Nearly all of the women we spoke with described elaborate kinship networks, often made up of extended family members or friends, whom they depended on for economic, social and medical support when confronting their HIV diagnosis, and making decisions about HIV treatment and care. This support appears to have been offered both in times of crises, and in day-to-day activities and interactions. Although educational and employment institutions were often lacking in these women's lives, they reported extremely strong ties to religious institutions, frequently citing their relationship to God as a primary motivation to accept their HIV diagnosis and treatment.

These findings are consistent with studies that have demonstrated the strength of kinship networks in Northeastern Brazil (Borges, 1992; Rebhun, 1999). In particular, scholars have pointed to extended family members' willingness to stand in for one another, forming makeshift "families" which shift and change depending on circumstance (Scheper-Hughes, 1992). Although, these cultural features of Northeastern life were clearly extremely important in helping mothers cope with episodes of depression, and in their attempts to develop healthy routines, to take medications, or simply to find reasons to continue living, we want to emphasize that these struggles occurred in a context of a particular set of health policies and practices, that appeared to provide additional levels of support for these women.

Conclusion

Despite a steep decline in the overall prevalence of perinatal HIV transmission in Brazil, data from the city of Fortaleza indicate that HIV positive women remain at risk for the transmission of HIV to their infants (Maia, 2008). The results of our study indicate that one of the factors in ensuring that women actually take advantage of the medical treatment and care they are offered is doctors' attitudes and the overall environment of care in which they disclose their HIV status and receive treatment. The women we interviewed consistently linked their perceptions of doctors' attitudes and the overall environment in which they received care with their willingness to attend prenatal care appointments, take an HIV test, and disclose their HIV status to caregivers - all crucial steps in reducing perinatal HIV transmission. Limitations to our study, such as small sample size, prevent us from being able to make conclusive statements regarding the role of a health care ideology in the experience of patient care, however we believe that our results reveal the need for more research that explicitly investigates the link between ideologies of health care, such as a human rights

approach to health, and critical health outcomes that depend heavily on the physician-patient relationship.

Acknowledgments

The authors would like to acknowledge Simone de Sousa Paiva who served as the proxy interviewer for this research. The National Science Foundation, RUI Grant # 0647112 provided funding for this work. Cait Breen provided graphic and bibliographic assistance. Stacy Lindau's effort on this manuscript was supported in part by NIH/NIA 1K23AG032870-01A1.

References

- Biehl, J. *Will to Live: AIDS Therapies and The Politics of Survival*. Princeton: Princeton University Press; 2007.
- Boletim Epidemiologico . Boletim Epidemiologico Aids-DST. Brasilia: 2010.
- Cseste J. Several for the Price of One: Right to AIDS Treatment as Link to Other Human Rights. *Connecticut Journal of International Law*. 2001; 17:263–272.
- Farmer, P. *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press; 1999.
- Galvao J. Brazil and Access to HIV/AIDS Drugs: A Question of Human Rights and Public Health. *Chicago Journal of Public Health*. 2005; 95(7):1110–1116.
- Goldani M, Giugliani E, Scanlon T. Aconselhamento e testagem voluntaria para o HIV durante a assistencia pre-natal. *Revista de Saude Publica*. 2003; 37(5):552–558. [PubMed: 14569329]
- Greco D. Brazilian policy of universal access to AIDS treatment: sustainability, challenges and perspectivas. *AIDS*. 2007; 21(suppl 4):S37–S45. [PubMed: 17620751]
- Kreitchmann R, Fuchs S, Suffert T, Preussler G. Perinatal HIV-1 transmission among low income women participants in the HIV/AIDS Control Program in Southern Brazil: a cohort study. *BJOG: an International Journal of Obstetrics and Gynaecology*. 2004; 11:579–584. [PubMed: 15198786]
- Lindau ST, Jerome J, Miller K, Monk E, Garcia P, Cohen M. Mothers in the margins: Implications for eradicating perinatal HIV. *Social Science & Medicine*. 2006; 62:59–69. [PubMed: 15992982]
- Lindsay, AC., et al. *Publication of Maternal Health*. Fortaleza: State Secretariat of Health of Ceara; 2004. *Maternal Health Care Services in the State of Ceara, Northeast Brazil*.
- Maia, J. *Diario Do Nordeste*. Sabado; 13 de Setembro: 2008. Fortaleza e a 2nd capital do Pais em gravidas com HIV.
- Miranda A, Soares R. Mother to child transmission of HIV in Vitoria, Brazil: Factors associated with lack of HIV prevention. *AIDS Care*. 2005; 17(6):721–728. [PubMed: 16036258]
- Mofenson LM. Tale of two-epidemics – the continuing challenge of preventing mother-to-child transmission of human immunodeficiency virus. *Journal of Infectious Diseases*. 2003; 187(5):721–724. [comment]. [PubMed: 12599044]
- Okie S. Fighting HIV- Lessons from Brazil. *The New England Journal of Medicine*. 2006; 354:1977–1981. [PubMed: 16687709]
- Ramos M, Gregol L, Germany C. Prevention of Mother to Child Transmission of HIV: Compliance with the Recommendations of the Fortaleza National STD/AIDS Control Program for Prenatal and Perinatal HIV Testing in Porto Alegre, Brazil. *AIDS & Behavior*. 2002; 6(3):277–282.
- Safreed-Harmon K. Human Rights & HIV/AIDS in Brazil. *GMHC Treatment Issues*. 2008; 21(3-4):1–6. [PubMed: 19230303]
- Tidwell R. The No-Show Phenomenon and the issue of resistance among african-american female patients at an urban health care center. *Journal of Mental Health Counseling*. 2004 Jan.
- Tunala L. Fontes cotidianas de estresse entre mulheres portadoras de HIV. *Revista Saude Publica*. 2002; 36(4):24–31.
- Turchi M, Durate L, Martelli M. Transmissao vertical do HIV: fatores associados e perdas de oportunidades de intervencao em gestantes atendidas dem Goiania, Goias, Brasil. *Cad Saude Publica*. 2007; 23(3):1–12.

Table 1

Sample Population

	Fortaleza
Median Age	33 (23-43)
Living Below the Poverty Line in their respective countries	18/18
Finished High School	3/18
Every Formally Employed	7/18
Children (mean and range)	3 (1-7)
Routine Prenatal Care	12/18
Number of mothers with HIV positive children	1/18