HIV Positive & Pregnant: Defying the Social Order

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KEYWORDS: HIV/AIDS, PREGNANCY, PRENATAL CARE, HEALTH-CARE WORKERS, DISCRIMINATION, STIGMA, POWER

Enhancements in the medical management of HIV disease and improvements in sociocultural attitudes toward HIV-infected people have their limitations, even after 30 years of the pandemic. This appears to be especially true for HIV-positive women, particularly for those who become pregnant. Discrimination and stigma may be keeping this group of women from seeking prenatal care. To determine the extent to which this is true, this qualitative study was conducted using ethnographic inquiry to elicit HIV-infected women’s perceptions of how they were treated by health-care providers when they became pregnant. Life histories indicate that the women had negative experiences at some point during their pregnancies and continue to face opposition from the health-care system that is meant to nurture them through their childbearing years. Given the significant public health implications of HIV-positive women becoming pregnant, improvements are needed to improve the approach that health-care providers display toward HIV-positive, pregnancy women.

In 1994, clinical trials revealed that zidovudine® (AZT, ZDV) administered after 14 weeks of pregnancy and during delivery, and to newborn infants for six weeks postnatally, dramatically reduced the rate of perinatal infection from 25.5% to 8.3% (Connor et al., 1990). Additional research since then has demonstrated the effectiveness of various antiretroviral therapies in combination with cesarian section to decrease the risk of perinatal infection to about 0.4 (Centers for Disease Control and Prevention, 2009). Before there were treatments preventing perinatal transmission of HIV, the number of infants born infected in the United States peaked in 1991 at 1,650; by 2005, only 67 children were infected with HIV perinatally (Centers for Disease Control and Prevention, 2007), making perinatal infection a rare occurrence (Buchanan & Cunnigham, 2009).

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Advances in HIV/AIDS treatment and survival, particularly related to HIV-related pregnancies, present an anomaly. The success of antiretroviral therapy (ART) in reducing HIV perinatal transmission is predicated on its administration throughout pregnancy. Despite this, providers have not been diligent enough in encouraging pregnant women to get tested (Olges et al., 2007) even though one in five Americans is unaware of their HIV status (Buchanan & Cunningham, 2009). In states with opt-in testing for pregnant women, in which women are offered an HIV test and must provide consent, prenatal testing rates range from 25% to 69% (Alverson & Alexander, 2009). This suggests that there are still many women living with HIV who may not be receiving the current standard of care for HIV and pregnancy, which raises important questions about the quality of care these women are receiving.

The nature and the quality of the care that a woman living with HIV receives is vitally important. This may be especially true for HIV-positive women who become pregnant. Therefore, health-care workers should be willing to discuss the possibility of HIV infection and pregnancy and be able to objectively present the benefits and risks of perinatal transmission and antiretroviral therapy during pregnancy. Unfortunately, the impact of the myriad psychosocial factors surrounding HIV infection and pregnancy is proving to be significant.

Because HIV and AIDS continue to carry enormous social stigma, some health-care professionals may still doubt the appropriateness of childbearing by women living with HIV. From the early days of the AIDS epidemic, when women living with HIV were advised against pregnancy (Fekety, 1989), to the present mood of moral rectitude, women living with HIV seem to be facing continued opposition from the same health-care system that is meant to nurture them through their childbearing years. For the woman who does not receive any prenatal care or who receives inadequate care, the risks to maternal, fetal, and infant health are much greater.

Herek (1990) suggests that AIDS-related stigma is best understood through psychological and sociological perspectives on stigma, prejudice, and attitudes—AIDS gives many people a convenient excuse for prejudice and for a kind of preexisting hostility. Foucault’s premise that power creates a force that produces the corpus of common knowledge (Foucault, 1972), implies that the power/knowledge paradigm exerts considerable influence in determining what constitutes deviant behavior. By depicting people with HIV infection as deviant, the group in power can legitimately exclude them from society (Rochon, 2008). Thus, pregnant, HIV-positive women become stigmatized on multiple levels: they are mostly people of color; they are often poor; they are females who by their very biology are second-class citizens; they are
HIV-infected; and they are declining to accept their lower social status by rebelling and carrying through a high-risk pregnancy (Rochon, 2008).

Human experience has long been viewed from the one-sided perspective of the male gender (O’Brien, 1982), which projects male domains of experience as “cultural truths” (Clifford, 1986). Feminist anthropology has developed in response to this dominance of men and their particular viewpoints within the field. Feminist theories of health and illness provide another counterpoint to the patriarchal position of privilege, which attempt to demonstrate that women’s experience of health is “socially constructed rather than built directly upon biology or the materiality of the body (Annandale & Clark, 1996, p. 19). The medical profession is regarded as a patriarchal institution that uses definitions of illness and disease to perpetuate women’s inequality, taking control over certain area of women’s lives, such as pregnancy and childbirth (Lupton, 1997). These frameworks offer a feminist understanding of the complex place of women in the AIDS epidemic.

The continued perception of AIDS as a socially stigmatized disease, and its resultant power over women’s lives in so many spheres, is compelling. Therefore, a careful examination of the conditions that affect women’s lives means that women living with HIV must be considered as more than “victims, vectors, or vessels of HIV (Schneider & Stoller, 1995). Rather, women should be viewed as “actors pursing creative and effective strategies which challenge… gender inequality and enforced passivity (Schneider & Stoller, 1995). The goal of this study was to draw attention to these challenging circumstances faced by women living with HIV who become pregnant. To assess the psychosocial and emotional treatment that these women have received from their health-care providers, as well how this treatment might have affected their willingness to seek prenatal care, the objective was to elicit women’s perceptions of their care during health-care encounters related to pregnancy. Examining women’s prenatal care experiences could provide insight into overall conditions that women living with HIV face when considering pregnancy.

METHODS

This qualitative study used ethnographic methods to focus on the description of a particular subculture—defined as “the commonly shared customs of a group within a society” (Ember & Ember, 1993, p. 17), in this case, women living with HIV—to uncover patterns and themes emerging during prenatal care. The main features of the study were the collection of data using closed-ended and open-ended surveys to collect demographic and health status information; in-depth, semi-structured interviews; input from key informants; life histories; and thick
description. The latter refers to descriptions that make explicit the detailed patterns of cultural and social relationships among women living with HIV and gives readers a sense of the emotions, thoughts, and perceptions that informants experience within their communal setting (Holloway, 1997).

Ethnographic inquiry and life history methods were used to investigate how women living with HIV who are pregnant or have had children since being diagnosed with HIV are treated when accessing health-care or social services. These methods facilitated in-depth understanding of women’s experiences. Drawing on Spradley’s (1980) approach to ethnographic inquiry, participants were asked “grand tour” questions to gather information about the general features of their lives. The interviews continued with “mini-tour” questions to catch the smaller and more detailed aspects of women’s experiences (see Appendix A). During these face-to-face, in-depth interviews, an effort was made to capture the informants’ life histories, defined as a form of narrative in which an individual provides a retrospective report of her own life and development (Holloway, 1997). Life histories help researchers understand the personal lives of people within a culture; more importantly, they may teach investigators about the person’s culture and its values and norms. If conducted successfully, they can lead to an understanding of the reasons for people’s beliefs and behavior (Holloway, 1997). To obtain an entire life history, however, “would require recording all the talk ever produced by a given speaker” (Linde, 1993, p. 51). Since this is not practical, the alternative is to collect a partial life story, or “a temporally discontinuous unit” (Linde, 1993, p. 51), that tells “‘what events have made me what I am’ or more precisely, ‘what you must know about me to know me’” (Linde, 1993, p. 20). This can be done by using interview data that focuses on a particular theme, event, or time in a person’s life.

Carspecken (1996) suggests that the best role for a qualitative interviewer is that of a facilitator who constructs a supportive and safe normative environment for informants and helps them “to explore issues with their own vocabulary, their own metaphors, their own ideas” (p. 155). This approach allows the cultural themes operating within the informant’s life to be revealed through her own words and remembered experiences. The researcher should be able to pick up on those cultural themes and continue exploring them through responses to the informant’s disclosure. Allowing women the freedom to tell about the parts of their lives that they consider the most important produces the most internally valid stories that reveal the cultural themes used to talk about pregnancy and HIV.

Transcriptions were analyzed using discourse analysis, which provides a way to examine how social reality is constructed through
interaction and conversation. It is based on the idea that language does not just echo the world of social members and cultures but also helps construct it (Holloway, 1997). In searching through the text, commonalities and similarities are grouped together so recurrent ideas and consistent patterns are emphasized. These closely linked concepts can then be grouped into themes. Thus, broad patterns of thought and behavior appear (Holloway, 1997) that can then be used to make inferences, provide meaning, and offer explanations for the phenomena observed. Four major themes emerged from this process: positive attitudes, negative attitudes, birth outcomes, and maternal concerns. Of these, the first two relate directly to the participants’ perceptions of and experiences with health-care workers’ attitudes toward them during prenatal care. The other two are tangentially related to attitudes because they highlight the role that stigma and power played in creating challenges and psychosocial barriers to care for these women.

Recruitment
As in other qualitative research, purposive sampling was used. The target population was HIV-positive women with pregnancy experiences. Participants were recruited from eight local AIDS Service Organizations (ASOs), six clinical care facilities; and at the Harris County Sheriff’s Department (the county jail facility) in the Medical Services Division. These organizations provided a good cross-section of individuals with diverse socioeconomic, psychosocial, and demographic backgrounds. From the pool of 31 women who completed the survey, a small convenience sample of four was chosen to be key informants for the in-depth interviews (ethnographic inquiry and life stories). They were selected because they were more readily accessible in terms of residential stability and substance abuse history. The women were able to provide first-hand accounts of the kind of treatment they had received during their pregnancies. The women received a small incentive of gift coupons for McDonald’s®.

The interviews, which were conducted by the principal investigator, were audio-recorded with the permission of the informant and lasted between 35 to 70 minutes. Saturation was reached to the extent that the description of interesting observations in a small number of participants was achieved. Each of the women described negative treatment experiences and unsupportive attitudes from health-care workers.

Human Participants
Individuals living with HIV are generally considered to be a vulnerable population because of the risk of stigmatization, should their HIV status be revealed. Because the researcher had an ongoing and
productive working relationship with many of the local ASOs, obtaining the cooperation of these agencies in recruiting study participants was not problematic. Additionally, the researcher has sustained a connection with various women living with HIV who are considered to be gatekeepers to certain groups of Houston’s HIV-positive population. They are familiar with the researcher’s reputation and integrity and were willing to endorse the study to women in the community, thereby facilitating contact with people from the sampling frame.

The study was submitted to and approved by the Committee for the Protection of Human Subjects (CPHS) at the University of Texas Houston Health Science Center. Every person enrolled in the study was required to sign an informed consent document that outlined the purpose of the research, the requirements of participation, the participant’s right to refuse to answer any question, and the possible risks and benefits of participating in the study. Participation at all levels was voluntary; declining to participate did not affect any treatment or services that a woman might be receiving from an ASO or a health-care provider. All materials were kept strictly confidential and identifiers were absent from survey instruments. Audio recordings made during the interviews were done with the expressed permission of the informants and did not contain names.

THE WOMEN

Annie\textsuperscript{2} is a married, 32-year old Caucasian woman. She has been living with HIV for 15 years and has been on ART for many years. She has had one pregnancy, which resulted in a miscarriage. When she became pregnant, she consulted an obstetrician who told her that she would have to see another doctor for her pregnancy. Although the physician was professional in manner, she found him reserved and impersonal, leading her to assess the quality of her health care as fair. Annie has always wanted children and still hopes to have one soon.

Diane, a divorced, 32-year old African American woman, has been living with HIV for 11 years. She has had four abortions, two before becoming HIV-infected and two after. Her fifth pregnancy resulted the birth of a healthy girl. For this pregnancy, she went to see a family practitioner who is also an HIV specialist. She was treated in a supportive environment with the advice that it was all right to be pregnant but that she would have to take medications during the pregnancy, so she feels that the care she received was excellent. She has had a tubal ligation so is unable to have any more children.

\textsuperscript{2}The names of all informants and family members have been changed.
Karen, a married, Caucasian woman, is the oldest of the group at 39; she has been living with HIV for 10 years and takes HIV medications. She sought infertility treatment, which was unsuccessful, and also began adoption procedures but cancelled them when she became pregnant. Of her two pregnancies, one ended in a miscarriage while the other resulted in the birth of a healthy girl. The obstetrician that she saw for her pregnancy was professional but impersonal, addressing her in a closed and reserved way when telling her that she would have to take medications during the pregnancy. She felt that her medical care was fair. Karen will only have one child to avoid the stress involved with such a high risk pregnancy.

At 23, Laura, who is the youngest of the informants, is a divorced, Hispanic woman. She has been living with HIV for seven years and takes HIV medications. Although young, she has been pregnant six times, has had three miscarriages, and three live births, all of them healthy boys. She went to see an obstetrician who did not have a noticeably negative reaction to her pregnancy but he did tell her that she would have to see another doctor for care. She found his attitude to be fair. Laura enjoys being a mother and wants more children.

THE STORIES

The women were encouraged to discuss their pregnancy experiences in their own way: Laura and Karen each began by describing their first pregnancy, while Diane voiced her general impressions about the care she received and Annie recalled her experiences with general gynecological care. Rather than interjecting questions and disrupting the flow of each woman’s life history about her HIV status and health-care experiences, the women were allowed to reflect on their past and to organize their thoughts in a way that made sense to them. This provided a clearer picture of the sociocultural context of these women’s lives and some explanation for their pregnancy decisions.

Positive Attitudes

Most of the references to positive attitudes or support had to do with family members or friends. Annie said, “It was the two moms [mother and mother-in-law] that were the most supportive.” Karen, who had previously had a miscarriage, said of her second pregnancy,

My mom and dad were excited... especially after the first trimester, they just couldn’t wait! My two sisters, they were very supportive and made sure that when Sam [her husband] was out of town when I was pregnant that somebody was with me. And friends,... everyone that knows my status was very supportive!
With the first pregnancy, I think they felt just as bad as I did when I miscarried.

Diane recalled telling her parents that she was pregnant: “They were able to be as supportive as they could be in light of the situation, because they didn’t know [whether the baby would be HIV positive]... They’ve always been a great family; they have just always been there.”

The women also reported some positive experiences surrounding their medical care during their pregnancies but this may be due in part to the fact that these women had at some point consulted a family practitioner, infectious disease specialist, or obstetrician/gynecologist who regularly treat patients infected with HIV and so were more informed about the risks and realities surrounding HIV-positive pregnancies. In spite of this, the women were not particularly effusive in their praise although they related some occasions when medical personnel were supportive. Diane said that her physician and the nursing staff were great. She felt like she could pick up the phone anytime and call for information, which reduced her anxiety. Karen found that the male nurse who checked her in when she was admitted for labor was very nice. Laura, who was living in a transitional housing facility, said that the staff was embracing and supportive as they “watched her go through a pregnancy.” In fact, “they treated me better than my doctor’s staff treated me.”

Negative Attitudes

Despite having received most of their care from HIV specialists, the women were at some time treated with a great deal of negativity from providers, medical staff, family. After her miscarriage, Karen revealed that “it brought out... naysayers. One was my sister because when I told her I was pregnant she said, ‘How far along are you?’ I said eight weeks and she said, ‘Oh, well, you’re still early enough to miscarry.’” Annie had a similar experience, not only because she miscarried but also because some of her family reacted in the same way: “Despite people having the best intentions... Ken’s [her husband] dad and my dad said after I miscarried, ‘Good; they shouldn’t be having children anyway.’”

The women had more obvious negative reactions from medical staff. After Diane delivered her baby, her nurse came in and treated her roughly.

She didn’t look at me but she came in and she said, “Give me your arm.” So I gave her my hand and she started trying to poke the IV. There was no conversation, there was no explanation as to what she was doing, and she was extremely rough and very, like,
“What the fuck?” She was just going to get it done and she was getting out and you could tell. It was very, very obvious… Because she couldn’t find one spot, she tried to do another spot and then, by her body movements and everything, that this was not some place she really wanted to be and this was not a job she wanted to do. Oh, well, not everybody is going to be down with this and it’s sad. But you know, I’ll see you two more minutes and then you’ll be gone and I won’t deal with you no more!

For Laura, the problem occurred with the physician who delivered her first son. “He quickly said, ‘Oh, no, I can’t deal with you.’ This was one of those old black men who was like, ‘Oh, no, I don’t want to catch that from you.’” She mentioned that the staff at the doctor’s office and some of the social workers at some of the agencies where she received services were also mean, making comments like, “Why are you having more babies?” and “Why are you having babies when you’re HIV positive?” When Karen had to go to the emergency room to get treated for an adverse reaction to the HIV drugs she was taking, the doctor made her feelings known.

The doctor came in, Miss Prissy Little Thing, and she went over my chart and she goes:

Doctor: You’re pregnant?
Karen: Oh, yeah! I am!
Doctor: And you’re positive?
Karen: Positive I’m pregnant? Yeah.
Doctor: No, you’re HIV positive.
Karen: Yes, I am.
Doctor: And you’re pregnant?
Karen: Yes, I already answered that question. What else do you want to know?
Because it really ticked me off, that in this day and age, that with a doctor there would be that prejudice and it just floored me. I truly regret that I didn’t call her on the carpet and nail her to the wall.

Some of the women were uncomfortable with their care providers because they did not exhibit confidence or understanding about HIV infection or of the issues involved in pregnancies for women living with HIV. For example, the physician that Annie went to after discovering that she was pregnant told her that he did not have a problem treating her even though she was HIV positive. She reacted to this statement by saying to him:
'Well, okay, you don’t have a problem treating me, but I need AZT during labor... and I need AZT starting my fourteenth week of pregnancy and the baby needs six weeks of AZT follow-up and then Bactrim.' I just rattled this off real quick and he looked at me and said, ‘Okay, I’ll refer you.’ He immediately was overwhelmed with having to go over all the restrictions, knowledge, to do it... That statement, ‘I don’t have a problem with you.’ I didn’t know if it was condescending or perhaps you don’t know the information that’s needed to care for me.... Why would I put my stuff, you know, my life, my child’s life, in your hands when you don’t know these basics?... How am I going to trust that you’ll know which milligram to prescribe me for AZT?

There were other instances when providers’ impersonal approaches caused the women to question their sensitivity. According to Annie, the doctor came in after her dilatation and curettage and said, “‘Well, we found dead tissue, so it wasn’t a viable pregnancy.’ That was how he phrased it. It was very cold, clinical... I wasn’t thrilled with his sensitivity.”

Similarly, there was ambivalence on the part of providers, which became evident with planned versus unplanned pregnancies or with additional pregnancies. It was common for the women to be treated with respect and support if it was assumed that the pregnancy was unplanned. However, if a woman approached the topic of becoming pregnant or went to the same provider seeking care for another pregnancy, there was a noticeable shift in attitudes. People expressed their feelings about this in different ways. When Annie talked about her miscarriage to one provider, the physician commented, “I’m so sorry… It’s not like you can go and get immediately pregnant.” Annie asked her to clarify what she meant by the comment, to which the doctor replied, “Because this was an accident,... [people] could support you on it, but... it’s not like you could plan it and get their support.”

Annie believes that there are judgments surrounding women living with HIV who have more than one pregnancy. She has overheard social workers refer to these women as “repeaters.” Her impression is that they are understanding of an HIV-positive woman having one child but “two is pushing your luck and people are kind of pissy about it. They make derogatory comments about HIV-positive women and them continuing to have babies.” When Laura was pregnant with her third child, the staff at the doctor’s office treated her badly: “…like I shouldn’t be pregnant or something because I’m positive.” Two years later, after a miscarriage, Laura found that the same person was “acting all crazy with me because I got pregnant.”
The health-care worker’s attitudes also changed in the way they treated the women before they became pregnant compared to after they presented with a pregnancy, regardless of whether it was planned or unplanned. Staff was generally considerate but some became closed and reserved once their patient became pregnant. Laura commented that her provider talked behind her back and gave her dirty looks. She summed it up by saying, “If they find out they’re positive during their pregnancy or right before and they couldn’t do nothing to stop it, then that’s different. But if you’ve been HIV-positive for years, you shouldn’t have no kids.”

Birth Outcomes

This theme, which has to do with the outcomes of the women’s pregnancies, draws attention to the ways in which the women were led to make certain decisions based on the attitudes or feedback from providers or family. Between them, the women experienced a total of five miscarriages and two abortions. Annie and Karen both questioned why they had had miscarriages, suggesting that they may have been caused by the antiretroviral medications they were taking at the time they became pregnant.

Laura was only 13 years old when she became pregnant the first time before she was HIV-positive. She revealed:

When I was 13, my mom used to make me have sex with her husband to try to get me pregnant from him. I was pregnant from him and went through a trial of depression and tried to commit suicide twice that year… I used to punch myself in my stomach so I had a miscarriage when I was 13 ’cause I was pregnant by my mom’s husband.

Of one of the other miscarriages, she explained,

I did get pregnant from my husband, but I had a miscarriage. He beat it up out of me. Well actually, we both did, ’cause we was always fussing and arguing and fighting. He never actually just punched me in my stomach or anything. I lost the baby more due to stress and emotional stuff, you know, which took a bearing on my body.

She became pregnant again when she was 15 by someone she had been “messing around with” and when she was about four months

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3 The state of Texas has mandatory reporting requirements for the sexual abuse of minors. Because this participant was an adult when this interview took place, there was no responsibility to report the rape that occurred when she was a minor.
pregnant, her uncle raped her. It was as a result of the rape kit that she found out she was HIV-positive. Her miscarriages could be due in part to violence. Laura’s history of multiple pregnancies, miscarriages, and abuse is a common occurrence for many poor, minority women; it typifies Herek’s (1990) notions on AIDS-related stigma and hostility and exemplifies the multiple levels of stigmatization that women living with HIV can experience.

The significance of the power that health-care providers have over patients is illustrated by Diane’s abortions and eventual tubal ligation. She had the abortions because she was afraid that the baby would be infected with HIV but she also attributed her actions to not having the information about perinatal transmission rates. She remembered,

> We never really talked about it, but I know retrospectively for me, it was like, “You sons of bitches!” That’s fucked up, you know, that’s real shitty! That I had to make that kind of decision and not knowing I didn’t have to make that kind of decision.

At one point, she stopped to wonder aloud how many other women may have had abortions because they did not have the information or were misinformed about the risks. A more overt illustration of this influence is evidenced by the tubal ligation that she had immediately after the birth of her child. According to Diane,

> ...it was natural, quote-unquote, to do that. If you’re positive and you’re going to have a kid, then your next step before you leave the hospital is to make sure your tubes are tied.... You [the physician] made it clear that this is what we’re supposed to do, because we’re not supposed to bring babies into the world and then die and shit. You cut off a reproductive tract of a 25 year old woman, with her permission, because you convince her that this is the right thing to do!... They really made the tubal thingy logical, they made it the only option... That sealing off of options is critical for women.

Although she was comfortable with her earlier decisions to abort, this irrevocable act elicited a different reaction from her. It came up several times during the interview, along with the fact that she was angry over losing her choice to have more children, which she said she would have wanted to do now that there are treatments that greatly reduce the risks of perinatal transmission. Later, however, she seemed

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4 See footnote #2.
more resigned to her circumstances: “I realize now that you’ll never have all the information, so let me make my own decisions about what I’m going to do because today I might have three kids instead of just one!”

The other area related to this theme is adoption. Diane mentioned it as an option in light of the tubal ligation but has not acted on it, whereas Karen did originally set out to adopt a child. Both of the women talked about the negativity that seems to be prevalent when individuals or couples living with HIV attempt to adopt. The women were also unambiguously reminded of the discrimination that still exists. Karen and her husband found out that most of the agencies were not receptive to HIV-positive couples adopting children—unless they were willing to take in a severely handicapped child. Karen felt that:

It was a way of saying, “We know you don’t want a handicapped child and if that’s all we offer you,… you’ll go away.” I was pissed at the time and I threatened a lawsuit against one of them… That shut that one up really fast… But I told her that I wouldn’t want to work with her because I didn’t like despicable people.

Surprisingly, a social worker at one of the agencies contacted Karen, told her that she did not agree with those types of policies, did the home study, and then signed off on the process so they could do an international adoption. Shortly thereafter she found out she was pregnant and decided not to go through with the adoption.

Maternal Concerns

The final theme that emerged relates to the women’s concern for their babies’ health and disclosure of their own HIV status, both of which encompass elements of stigma and power. All the women talked about their fears of infecting their child, of the stress involved in having to wait to find out if the baby would be HIV-negative, referring to the amount of time that it took then to determine definitively whether or not an infant had HIV. Diane feels that her choice to have abortions was “psychologically logical in order not to have to go through… havoc… two years of wondering.” Karen found the pregnancy emotionally trying, wondering what she had done and how she would handle it if the child were positive. She felt so strongly about this that she and her husband decided that they will not have any more children, that they will not “tempt fate again” even though transmission risks are now negligible (Buchanan & Cunningham, 2009).

The possibility of their own shortened survival time amplified the women’s anxiety. Annie’s husband reacted to the news of her pregnancy with anger and fear:
At that time, his T-cells had dropped to 16 and he thought he was going to die in six months after our marriage; he was just convinced he’d be dead then. So, to turn around and be pregnant when he thought he’d be dead in six months, so he wouldn’t be here to raise it, just hurt him so enormously and scared him.

An adoption agency employee told Karen that she was not going to live long so the adopted child would be without parents.

The prospect of disclosure, whether of their HIV status or their pregnancies, also weighed on the women. Annie went to a clinic further away from her home so that people would not find out she was pregnant. Karen was so discouraged by the reaction of some of her family to her first pregnancy that she told only half of them when she became pregnant again. She was also concerned that members of her husband’s family who did not know her HIV status would be alerted if they came to the house and saw the baby’s prophylactic HIV medications. When Annie went for her dilatation and curettage, the nurse informed her that she had to be tested for HIV; rather than disclose her status to others in the procedure room, she let them test her.

LESSONS LEARNED

The anecdotal information from these life histories, which includes tangible evidence of inappropriate comments and treatment, supports the suspicion that when a woman living with HIV reveals she is pregnant, she is likely to be subjected to negative attitudes from health-care workers, family, and friends. It would be easy to conclude that flawed communication or displays of discomfort are merely an outcome of a poor interaction styles or unfamiliarity with HIV disease but to do so would be pardoning people for their ignorance and for their value-laden judgments. It has been over 30 years since the AIDS pandemic first appeared on a worldwide scale. The facts about transmission, including the rates for perinatal risk, have been well publicized by the media, through educational programs, and even through popular culture (e.g., films, books, and television programs); this information is readily available to everyone at all levels of society. The incongruity of the gap between the plethora of information about perinatal transmission risks and the apparent continued negativity and ignorance suggests a lingering existence of the stigma surrounding HIV infection.

The unsupportive reactions experienced by the women in this study are a reflection of how our society continues to deal with HIV/AIDS. Although the simple solution would be to seek care from HIV specialists who tend to provide a more supportive environment, the
fact is there are enduring institutional and cultural obstacles against pregnancy in the context of HIV infection. The feedback from the four women about birth outcomes and maternal concerns has not only provided some interesting insights into their lives but has also led this investigation into an unexpected direction with regard to stigma and power. Rather than addressing the social values that surround HIV infection, some health-care workers continue to exert power over women by marginalizing them and diminishing their ability to control pregnancy. It reveals how individuals react personally and collectively to the issues: clinicians are first and foremost members of a society in which HIV-positive pregnancies are considered morally wrong; their reactions are merely a logical outcome of existing cultural norms.

We learned during the interviews that women often avoided disclosing not only their HIV status but also their pregnancies. What should be a happy time of sharing pregnancy experiences becomes a secret time shrouded in fear of retribution and hostility. Instead of receiving reassurances from care providers about the efficacy of ART during pregnancy to decrease HIV perinatal transmission, the women were confronted on a regular basis with negativity and judgmental attitudes from family, colleagues, and providers, all of which increased their stress levels and drove them further into secrecy. Whereas decisions related to disclosure or nondisclosure should afford women a sense of control and power over their own lives, the limited options that dictate what they ought to do about pregnancy in the context of HIV infection echo Goffman’s (1963) views on punishing those who rebel against social norms and values. The terminated pregnancies and reproductive outcomes that the women experienced expose the role of power that Foucault (1972) described. It was the adults in power who controlled Laura when they threw her out of the house or sexually and physically abused her. Diane’s tubal ligation was the result of a directive from the health-care authority and Karen was prevented from attempting adoption because of the position of the controlling agency.

Given the continuing prevalence of discrimination, bias, and stigma against HIV-positive women who become pregnant, one can conclude that these circumstances are having an impact on this group of women.

Ultimately, the most interesting finding from the emergent themes relating to HIV-positive pregnancies and societal restrictions is that women living with HIV want to have children. In and of itself, this is not surprising. The cultural “ideal” of motherhood and the notion of an innate maternal instinct persist (Burns, 2000; Morell, 2000). Gilligan’s (1982)feminist perspective on women’s decision-making and pregnancy challenged this notion by presenting notions of the interdependent self and other (p.74). Other researchers (Bradley-Springer, 1994; Pivnick, 1994; Radecki & Beckman, 1992; Ross et al., 1992) have delved into the
numerous reasons why women living with HIV might want to have children—to replace generations lost to poverty and crime, to have someone of one’s own, to correct the sins of substance abuse, to replace a child lost to HIV infection, or to deny the consequences of fatal disease. However, what surfaced from the interviews is that there were no ulterior motives behind the desire of these women to have children. Further, the HIV-infected women in this sample are not making random, irresponsible, or irrational decisions about their lives or their pregnancies, a finding consistent with Pies (1995). The interviews revealed that each of the women has her own set of sociocultural, economic, behavioral, and moral codes that guide her choices regarding pregnancy so that even in the context of HIV, having children is a highly personal matter. What was striking was that there were no rationalizations or justifications from the women. They simply talked about their desires for motherhood without putting any constraints on the notion. These women living with HIV seem to have insulated themselves to a certain extent from the persistent negative attitudes of health-care providers and society at large. The fairly high rate of pregnancies in this group suggests that these women have embraced motherhood in the same ways that HIV-negative women do (Ahluwalia, DeVellis, & Thomas, 1998; Sowell & Misener, 1997). Accordingly, to position childbearing by women living with HIV as a pathological or ethical issue ignores the circumstances of women’s lives.

By looking at the care that pregnant women living with HIV receive, this research has attempted to show how health-care workers’ stigmatizing attitudes toward the women combined with fear of recrimination might affect their willingness to seek prenatal care. Stigma and social exclusion associated with HIV and childbearing can have numerous effects, including a lack of emotional support (Carlisle, 2001). Having a child in an unsupportive environment can create negative reinforcements that decrease a woman’s sense of worth. Instead of perpetuating damaging self-images, care providers should be instrumental in building self-efficacy and self-esteem so that an HIV-infected woman’s experience of pregnancy is joyful rather than fearful. The main limitations with the study are selection bias as a result of the recruiting methods and the small sample size of women interviewed. In the first case, participants came almost exclusively from the client bases of ASOs. This meant that they were familiar with the services are available to people living with HIV infection, that they had probably used a variety of these services, and that they were more likely to find a supportive environment since these agencies specialize in serving this population. It would have been advantageous to request entrée to affiliated service providers that offer a broader range of services beyond HIV, such as county health clinics or health-care professionals who offer
more generalized medical care. While the sample population was representative of the national rates of people living with HIV infection, that is, predominantly minority and low income, an expanded recruitment base might have brought a greater response from Hispanic and Asian women. Moreover, by recruiting from private medical practices, for instance, family physicians or internists, information from women of different socioeconomic strata and with health insurance could have been collected information. Finally, a larger sample would have contributed to the generalizability of the results. The findings on the negative experiences of described in the life histories of these key informants cannot be used to make broad generalizations to all populations of women living with HIV who have had pregnancies.

Implications of the Findings

As an exploratory ethnographic inquiry, this study merely scratched the surface of what remains a highly controversial subject. A considerable amount of research still needs to be done concerning discrimination against pregnant women living with HIV. To adequately explore the attitudes of providers, interviews with clinicians, both HIV specialists and those who are not, need to be conducted to compare their viewpoints about HIV-positive pregnancies. Since infertility treatments and adoption were attempted by two of the women in the study, it would be informative to look more closely at the realities surrounding these options for women living with HIV. Regardless, the findings presented here are revealing in drawing attention to the fact that AIDS-related stigma persists.

There is an underlying assumption in the Western world that we have moved beyond the outdated and discriminatory views that many in the developing world still have about AIDS and toward women and their roles in society. We regularly react with horror to accounts of women in Africa, India, and the Middle East being shunned or punished for minor transgressions. Yet the truth is that these attitudes persevere in the western world. Recently, a judge in Maine revoked an HIV-positive pregnant woman’s release from jail on the grounds that he wanted to prevent her child “from being born HIV positive.” Although civil liberties advocates have secured her release, the battle continues to reverse her sentence entirely (Kolbi-Molinas, 2009).

In contrast, the success of antiretroviral treatment for pregnant, HIV-positive women in the United States (Buchanan & Cunnigham, 2009) has diverted our attention to developing nations to determine what innovative, cost-saving interventions could be used to prevent perinatal infection worldwide. To a certain extent, this focus on international HIV prevention has led to a situation in which a portion of the women in North America who are at high risk for an for an HIV-exposed
pregnancy will continue to be left out of education and prevention efforts that would bring them into prenatal care to receive treatment early enough in their pregnancies to reap its benefits. The information gathered in these life histories confirms this.

The public health implications of HIV-positive women becoming pregnant are great since HIV affects all individuals, regardless of socioeconomic status, gender, sexual orientation, age, or ethnicity. Since all of the women in this study experienced some censure before, during, or after their pregnancies, government, society, and health-care workers must work diligently to bring those most in need into a new, caring, and inclusive health-care system. Rather than focusing solely on the potential risks of an HIV-positive pregnancy, health-care workers should offer prenatal care to women living with HIV the way they would for any woman facing a difficult pregnancy (Rochon, 2008) — with compassion and consideration. By enhancing the quality and amount of prenatal care available to women living with HIV and by enabling them to make responsible decisions regarding childbearing, the long-term benefits would be reduced incidence of perinatal infection and decreased morbidity and mortality in HIV-positive women and their infants.

Feedback from this study reinforces the researcher’s initial concerns that HIV-infected women who become pregnant face serious challenges when seeking prenatal care. Because reproductive decisions are crucial to biological and social life, reproductive choice is among the most basic and cherished components of women’s rights to autonomy and privacy (Levine & Dubler, 1990). Therefore, HIV-infected women, like all women, should be free to make choices that are consistent with their cultural, religious, and personal values (Levine & Dubler, 1990). Emphasizing the moral responsibility of women living with HIV to avoid having children is clearly objectionable; attempts to influence childbearing, no matter what the mother’s circumstances, raises profound ethical, moral, legal, and policy issues.

If we accept that the behavior of health-care providers can have a profound affect on a woman’s well-being and how she feels about herself, it is essential that we develop methods to improve the approach that health-care professionals take toward HIV and pregnancy. Women with HIV infection should not have to deal with the added burden of stigma and control when making pregnancy decisions; they are already confronted with a barrage of social norms and personal factors that impact their pregnancy experiences. Understanding this can help decrease the stigma that the women may experience and increase their knowledge and power. It is hoped that the findings from this study can contribute in some way to future research on the attitudes of health-care workers toward pregnant women living with HIV.
Appendix A
Interview Questions and Probes

Grand Tour Questions and Probes
1. I would like to talk about your experiences when you first got pregnant after knowing you had HIV infection. Tell me how you felt.
   • Happy, sad, concerned, afraid?
2. Tell me about your experiences with your health-care provider when you got pregnant.
   • Did he/she make any suggestions about what you should do about your pregnancy?
   • Take HIV medications, Continue the pregnancy, have an abortion, see another doctor?
3. What was the doctor’s/nurse’s attitude toward you when he/she first told you that you were pregnant?
   • How were you treated by them during that time?
   • Were they supportive, could you ask questions, did you feel ok about being pregnant?
   • Were they unkind, did you feel uncomfortable, did you feel bad about being pregnant?

Mini Tour Questions and Probes
4. Do you think the doctor’s/nurse’s attitudes toward you were different before you became pregnant?
   • How were their attitudes different?
   • More or less supportive, more positive or negative?
   • What about after you were pregnant?
   • More or less supportive, more positive or negative?
5. Tell me more about your thoughts and feelings related to these experiences with health-care workers.

REFERENCES


Rochon: HIV POSITIVE & PREGNANT

Conditions, Fatal Diseases, and Clinical Care (pp. 107-149).


