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"Out of all of this mess, I got a blessing": Perceptions and experiences of reproduction and motherhood in African American women living with HIV

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Abstract

HIV disproportionately impacts African American women of childbearing age residing in the Southern United States. Antiretroviral therapy has increased the quantity and quality of life for people living with HIV and produced viable and safe reproduction possibilities for women living with HIV. However, little is known about reproductive decision-making processes for African American women living with HIV. The overall goal of our study was to qualitatively explore perspectives related to reproduction and motherhood in HIV-infected African American women of childbearing capacity. HIV-infected African American women of childbearing capacity in South

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Carolina (N = 42) participated in in-depth interviews. Our respondents held positive views about pregnancy and motherhood, despite non-supportive pregnancy messages from interpersonal influences, including health care providers. Study findings uncovered the need for programs and interventions to support women's reproductive autonomy and focus on reducing conception- and pregnancy-related transmission risks to infants and uninfected sexual partners.

Keywords

African American women; conception; HIV; reproduction and pregnancy perspectives; reproductive decision-making

African American women of childbearing age residing in the Southern United States are disproportionately impacted by HIV. Although they constitute only 13% of the U.S. population, African American women have a rate of new HIV infection almost 19 times higher than that of White women, and nearly five times that of Hispanic women (Centers for Disease Control and Prevention [CDC], 2013b). Women in the South may be particularly vulnerable to HIV infection as this region has the highest AIDS prevalence in the United States (CDC, 2015b), increased levels of HIV-related stigma, and heightened levels of institutional racism and discrimination (Kerr et al., 2014; National Alliance of State & Territorial AIDS Directors & National Coalition of STD Directors, 2014). National trends have further indicated that the majority of women diagnosed with HIV are of childbearing age (15–44 years; CDC, 2013a, 2013b), which has serious implications for the reproductive desires and health care needs of this population.

Scientific breakthroughs in HIV treatment and care, particularly the availability of antiretroviral therapy, have been instrumental in both delaying the progression of HIV infection and dramatically decreasing the number of deaths in persons with HIV (Murphy et al., 2001; Palella et al., 2003). Further, the successful implementation and promotion of recommendations for universal prenatal HIV testing and counseling, antiretroviral therapy, and combination prophylaxis has reduced mother-to-child transmission (MTCT) to less than 1% in the United States (CDC, 2015a), offering viable and safe reproduction options for women living with HIV.

In spite of their HIV status, numerous research studies have revealed that HIV-infected women continue to express a desire for motherhood (Barnes & Murphy, 2009; Finocchario-Kessler, Sweat, et al., 2010; Kennedy et al., 2014). Traditionally, the role of motherhood is a transformative experience for many women, including those with HIV. Motherhood can provide women with love, acceptance, and a legacy for the future. For marginalized women, motherhood can offer the promise of a hopeful future that far exceeds their current circumstances (Collins, 1987; Ingram & Hutchinson, 2000; Levine & Dubler, 1990). Researchers studying HIV-infected women have found that the maternal role can positively impact a woman's self-realization and self-esteem by providing her a sense of normalcy (Barnes & Murphy, 2009; Finocchario-Kessler, Sweat, et al., 2010; Kennedy et al., 2014). Further, HIV-infected women have described motherhood as a reason to live and implement healthy life-sustaining behaviors, such as adhering to HIV treatment (Boehme et al., 2014). Positive attitudes toward the role of motherhood have been associated with increased

intentions to become pregnant and increased number of prior pregnancies in women with HIV (Kennedy et al., 2014).

While societal norms and expectations promote motherhood for many women, some HIV-infected women, particularly those who are underserved, are discouraged from becoming pregnant (Ingram & Hutchinson, 2000; Thornton, Romanelli, & Collins, 2004). The dissonance between these conflicting messages ultimately complicates the reproductive decision-making process for HIV-infected women, often leading to personal, internal conflicts (Barnes & Murphy, 2009; Ingram & Hutchinson, 2000; Kirshenbaum et al., 2004). Moreover, advising HIV-infected women not to have children is inconsistent with contemporary models of care that endorse “living with HIV” rather than “dying from” the disease (Watkins-Hayes, Pittman-Gay, & Beaman, 2012).

Current guidelines outlined by the CDC (2013c) and the American College of Obstetricians and Gynecologists (ACOG, 2010) promote reproductive choice and informed decision-making for HIV-infected women. This reflects a shift in the medical community’s historic view that HIV posed serious challenges for reproduction, as evidenced by earlier recommendations that advised HIV-infected women to consider alternatives such as adoption, donor insemination, and child-free living (Ethics Committee of the American Fertility Society, 1994; Thornton et al., 2004). Guidelines now emphasize that the reproductive rights and desires of HIV-infected women should be supported by offering women evidence-based preconception counseling before planning and conceiving a pregnancy to achieve optimal maternal-fetal health outcomes and reduce HIV sexual transmission risks to uninfected partners (ACOG, 2010; CDC, 2013c; New York State Department of Health AIDS Institute, 2010). Further, the United Nations has endorsed the principle that all women should have the right to “decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights” (U.N. General Assembly, 1979, p. 19).

To date, few studies have examined the social and medical influences that impact reproductive decision-making by HIV-infected African American women. Thus, the goal of our study was to qualitatively explore: (a) perspectives related to reproduction and motherhood in HIV-infected African American women of childbearing capacity, and (b) advice that women received from their health care providers about reproduction. A better understanding of HIV-infected women’s personal beliefs, experiences, and influences surrounding reproduction and motherhood is needed to effectively tailor the preconception counseling and health care provider advice that support an informed decision-making model.

Research Design and Methods

Recruitment and Data Collection Procedures

Criteria for selecting participants for the research study included: (a) self-identified African American, (b) female, (c) self-reported diagnosis of HIV infection, (d) between ages 18 and 49 years, (e) English speaking, and (f) residing in South Carolina. Participants were excluded for not meeting any of the above six inclusion criteria or being unable to become pregnant because of natural causes, an implanted contraceptive device, or other forms of

sterilization procedures. Women were recruited from five South Carolina clinics or AIDS Service Organizations (ASOs) through both direct and passive approaches, which included case management referrals, word-of-mouth, and recruitment flyers in the clinic/ASO setting. Prospective participants who expressed interest in the study were asked a series of questions to assess eligibility. All interviews and observations were conducted by the first author in a mutually agreed upon site optimized for privacy, comfort, and convenience. After completing the interview, participants were compensated $25 (USD) for their time and participation. Participants who referred prospective participants who subsequently enrolled in the study received an additional $5 (USD) per enrollee. Data were collected from June 2009–July 2010. Study protocols and procedures were reviewed and approved by the University of South Carolina Institutional Review Board for Human Use.

Instrumentation

The interview guide was semi-structured in nature. See Figure 1 for a full listing of interview questions. Interview questions related to four domains: (a) women's experiences living with HIV, (b) women's perceptions of the meaning of motherhood, (c) women's pregnancy intentions, and (d) the influence of women's sexual partners on their pregnancy intentions.

Additionally, we collected participant demographic information on age, ethnicity, number of children, education status, employment status, marital status, annual income, health insurance status, number of years since HIV diagnosis, clinic location, living situation, religious affiliation, and mode of HIV transmission.

Data Analysis

Interviews were digitally recorded, transcribed, and analyzed independently by two coders utilizing NVivo 8 software. A draft of the codebook was established prior to conducting interviews and searching for emerging codes in the data using the interview guide. After 20% of the interviews were transcribed, read, and analyzed by independent coders, researchers met again to discuss data derived codes (Maxell, 2005). These codes were compared to the previously developed codes and finalized through coder consensus. The final codebook was used to thoroughly analyze data from interviews by coding emerging themes, patterns, and perceptions from participant responses. After researchers independently analyzed the data, they convened to discuss emerging themes. Coding differences were resolved during the consensus process. Demographic survey data were analyzed using SPSS 16.0 for Windows.

Results

Socio-Demographic Characteristics of Study Sample

The study sample consisted of 42 HIV-infected women who self-identified as African American. Participants ranged in age from 19 to 49 years; more than half of the women were between the ages of 40 and 49 (52.4%), with a mean age of 37.7 (SD = 9.2). The women were predominately single (70.4%), Baptist (66.7%), unemployed (66.7 %), had an annual income of $10,000 or less (73.8%), and reported becoming infected with HIV through

unprotected sexual intercourse with a male (85.7%). Approximately 24% of the women lived alone; 50% lived with a family member; 14.3% lived with a partner or husband; and 9.5% lived in some type of transitional housing. Women in the sample reported a mean of two children (range = 0–7). Approximately 19% of the respondents had less than a high school education; 33.3% had completed high school or received a general equivalency degree; 38.1% had attended college; and 7.1% of respondents had a college degree. Roughly 42.9% of the women were uninsured, 47.6% received Medicaid and/or Medicare, and 9.5% received another form of health insurance. The length of time since HIV diagnosis ranged from less than 1 year to 29 years, with a mean of 10 years (SD = 7.8). The majority of participants (97.6%) were seeking care from a clinic or ASO located in an urban (52.4%) or rural area (45.2%).

Conception and Pregnancy Perspectives

In general, two distinct narratives described by HIV-infected women emerged related to reproduction: (a) avoidance of pregnancy to eliminate HIV transmission risks to an infant and (b) the endorsement of pregnancy, which fostered a sense of normalcy. The women discussed reproduction and HIV in the context of their personal outlooks and experiences as well as their global views about HIV-infected women and reproduction.

Avoidance of pregnancy—For those women who desired to avoid pregnancy, many discussed the experience or prospect of being responsible for the HIV-infected status of an infant. MTCT was seen as traumatic, selfish, miserable, and shameful. One young woman without children remarked:

> I don’t believe in bringing a child in the world because I don’t want them to have a miserable life. Kids don’t even ask to be in the world, so I wouldn’t jeopardize it just to get pregnant knowing what my status is. (Age 23, 0 children, Diagnosed in 2003)

Another participant, who was diagnosed with HIV during labor and subsequently learned that she transmitted the virus to her son perinatally, shared her thoughts concerning the prospect of having future children:

> I wouldn’t want to bring another baby in the world positive and I know it’s not guaranteed. It bothers me that when he gets a little older I’m gonna have to tell him about his situation [status]. (Age 32, 2 children, Diagnosed in 2006).

One woman described avoiding pregnancy as a practical decision and preventive strategy to completely eliminate HIV risks to the infant.

> I don’t think I could live with myself knowing that I actually did this [infected child with HIV] to my child. I mean, you know, we’ve got birth defects and stuff, but if it’s something that could be preventable, I think that’s preventable, so abstaining is the best shot for me. (Age 47, 2 children, Diagnosed in 2001)

Endorsement of pregnancy—Although some women were opposed to having children in light of HIV infection, other women endorsed reproduction and described counter perspectives. These women accurately reported HIV risks and intervention strategies to

decrease transmission risks. They endorsed pregnancy for HIV-infected women as long as women strictly adhered to evidence-based strategies to reduce MTCT. One participant noted:

> I feel pretty good about HIV-positive women having children if they do everything they're supposed to do. Make sure that you take your medication so you'll be undetected like myself and because there's a 1% chance that your child could have it. Your baby could live a normal life and you could live a normal life, you just make sure you take care of what you're supposed to do. I admire them for even doing that [becoming pregnant], because that means they're not, they're not letting that overcome their life. (Age 32, 1 child, Diagnosed in 2005)

Similar sentiments were shared by another participant with two children:

> I just think that they [HIV-infected women] need to get educated and know that in every situation there's always doubt but if you do what you need to do, you should be fine.
>
> Know all the birthing procedures, know that there are certain medicines that you can and can't take while you're positive, and make sure you get the AZT while you're in labor, whether it's vaginal delivery or C-section. (Age 33, 2 children, Diagnosed in 1998)

Another woman, who gave birth to four children subsequent to her HIV diagnosis, reported: "I'm living proof that you can have children and it [HIV] won't touch them, as long as you do what you're supposed to do and take your medicines" (Age 35, 5 children, Diagnosed in 1996).

Health care provider advice—Endorsement or avoidance of pregnancy was also influenced by health care providers' perceptions and advice about pregnancy for HIV-infected women. While some women reported not having conversations with their health care providers about pregnancy, others described the advice they received as supportive or non-supportive.

A participant recounted a medical encounter with her health care provider where she was encouraged to undergo a tubal ligation to avoid future pregnancies. Her physician's views were in direct conflict with her personal values about reproduction and respect for autonomous decision-making.

> Every visit they [health care providers] wanted to know whether I was gonna get my tubes tied. That [my status] shouldn't deter me whether I'm gonna have my tubes tied after having this baby… (Age 45, 1 child, Diagnosed in 1998)

Another participant stated that while her provider offered current, up-to-date information about preconception options, she sensed that some providers believed that women with HIV should not get pregnant. Such a restrictive viewpoint resonated with the participant.

> I feel that they give me good advice but I think a lot of them try to deter you from becoming pregnant because there's still a lot of health care providers that live with stigma. (Age 43, 2 children, Diagnosed in 1986)

A woman who was 24 and pregnant during the time of the interview described her health care provider's advice about pregnancy as supporting an informed reproductive decision-making model. The health care provider's advice aligned directly with her values related to living a normal life as a young woman infected with HIV.

> They [health care providers] got the same idea I have, you know, just because you're positive, you can live a normal life, as long as you take your medicine and do what you're supposed to do, they don't see why a pregnancy is not something that you can do. (Age 24, 1 child, Diagnosed in 2006)

Meaning of Motherhood

Despite women's distinct perspectives about conception and pregnancy-related risks, motherhood was important to the majority of the women and carried various meanings. In general, motherhood was a transformative, inspirational, and purpose-filled role. In some instances this newfound role and purpose was rooted in spirituality and a belief that HIV and motherhood represented a second chance that came from a higher power. Women who neglected their children in the past during periods of incarceration or drug use, desired a second chance at motherhood with existing children and/or future children. Approximately one third of the women participating in our study reported former drug and/or alcohol abuse. Motherhood post-HIV diagnosis for these women represented an opportunity to responsibly care for children. One participant stated:

> I hurt my kids a lot being in active addiction through their childhood life, you know. I apologized as being sober to, you know, working on my recovery. But today, I'm always there for my kids. We have very special bonds. (Age 44, 5 children, Diagnosed in 1981)

Another participant similarly described motherhood following an HIV diagnosis as providing a new outlook and inspiration for fostering a healthier, safer, and more viable lifestyle to fulfill her role as a mother.

> You know, sometimes, at first I didn't take it [HIV] serious. But then I had to change my life because I have two beautiful kids. And, I want to live, you know, and I was out there on them drugs and stuff and found out them drugs was killing me faster than the HIV was. And that made me want to take protection on my life. (Age 19, 2 children, Diagnosed in 2007)

Motherhood, for women who gave birth to uninfected children post-diagnosis, represented and reinforced life, hope, purpose, and normalcy. For some women, purpose was deeply rooted in spirituality and religious beliefs. Their spirituality offered greater perspective and acceptance related to becoming infected with HIV. One participant expressed:

> I mean, I think about it every day because I see my daughter every day, and that's the greatest gift that I could of got out of it was her. She's negative, she's healthy and she's happy, she's smart, she's beautiful. So, I mean, out of all the mess I got my blessing. (Age 33, 2 children, Diagnosed in 1998)

Relatedly, another participant expressed that she embraced the role of motherhood because it provided an opportunity to start over: "Motherhood is all that I've heard it to be and more. It

just seems like I've been born again and I have a whole new second chance at life" (Age 45, 1 child, Diagnosed in 1998).

Discussion

Previous studies have identified a range of individual, interpersonal, and institutional influences on HIV-infected women's childbearing decisions (Craft, Delaney, Bautista, & Serovich, 2007; De La Cruz, Davies, & Stewart, 2011; Kline, Strickler, & Kempf, 1995). Results from our study highlighted that HIV-infected women's perspectives related to conception and pregnancy were heavily influenced by their personal understandings of HIV and the risk of MTCT. For example, women who practiced and recommended pregnancy avoidance were fearful of the possibility of delivering an HIV-infected child. Those women who endorsed pregnancy were cognizant of the approaches to prevent perinatal transmission and were grateful to be able to assume the role of mother. Consistent with other studies, many women in our sample, in spite of their HIV status, expressed reproductive ideals and intentions that differed very little from those of uninfected women (Finocchario-Kessler et al., 2012; Kline et al., 1995; Sowell, Murdaugh, Addy, Moneyham, & Tavokoli, 2002), highlighting the importance of routine delivery of reproductive counseling to HIV-infected women (ACOG, 2010; CDC, 2013c).

Despite guidelines that promote informed reproductive decision-making for HIV-infected women (ACOG, 2010; CDC, 2013c; New York State Department of Health AIDS Institute, 2010), findings from previous studies have suggested less than optimal communication between health care providers and HIV-infected women about reproduction (Finocchario-Kessler, Dariotis, et al., 2010; Squires et al., 2011). In a cross-sectional study of 181 HIV-infected women who were predominately African American, 67% reported a general discussion about pregnancy and HIV with their primary health care providers; only 31% reported a personalized discussion about future childbearing plans and, of the personalized discussions reported, 64% were initiated by the patient (Finocchario-Kessler, Dariotis, et al., 2010). Finocchario-Kessler, Dariotis, et al. (2010) contended that HIV care providers and gynecologists could promote the appropriate delivery of preconception counseling and care with HIV-infected women by initiating discussions about reproduction with all women of childbearing age.

A lack of societal support regarding pregnancy has been frequently described by women with HIV in other studies; women were shown to perceive motherhood as a socially desirable and valued role, but also felt that the general public, families, peers, and health care providers believed HIV-infected women should not become pregnant (Barnes & Murphy, 2009; Ingram & Hutchinson, 2000; Kirshenbaum et al., 2004). As noted by Barnes & Murphy (2009), women appraised these contradictory internal and external influences and messages to make reproductive decisions. Compared to uninfected women, many HIV-infected women reported feeling pressured to justify their reproductive decisions, further complicating the decision-making process. However, for some women the desire to have children outweighs the internal and perceived external dissonance.

The stigma and lack of support for reproduction and motherhood experienced by women in our sample may have been heightened due to their location in the South (Foster & Gaskins, 2013; Kerr et al., 2014). Findings from the Women Living Positive survey suggested that HIV-infected women residing in the South were more likely than women in the Northeast or Midwest to experience societal stigma related to HIV-infected women and childbearing (66% vs. 52% and 55%, respectively; $p < 0.05$; Squires et al., 2011). Research has shown that multiple structural factors may exacerbate the effects of HIV-related stigma for African American women in this locale and of these circumstances. For example, the lack of acceptance and implementation of comprehensive sex education approaches in the U.S. South might increase HIV stigma as HIV-related stigma is more likely to exist in environments with less accurate information about transmission risks (Brown, Macintyre, & Trujillo, 2003; Sengupta, Banks, Jonas, Miles, & Smith, 2011).

In addition to heightened levels of HIV stigma in the South, the social and health care experiences of HIV-infected, African Americans may be further complicated by deep-rooted institutional racism and discrimination. For example, the history of slavery and discrimination is integral to the experience of racism for African Americans, which, in turn, promulgates socially marginalized, intersectional identities among HIV-infected, African American women. The caustic legacy of racism in the United States, which has been tangibly manifested as slavery, legally sanctioned segregation, and under-resourcing of African American populations (often referred to as Jim Crow), and present-day institutional and interpersonal discrimination, informs the framework for which African Americans perceive their experiences. Thus, HIV-related stigma contributes to progressive burdens on women who already experience discrimination related to gender and race (Earnshaw, Bogart, Dovidio, & Williams, 2013; Watkins-Hayes, 2014). While there have been some examinations of HIV-related stigma in the South, the mechanisms by which this impacts reproductive decision-making remain unclear. Researchers should explore this topic in greater detail to develop effective education programs to inform the reproductive decision-making process of potential mothers, health care professionals, and public health practitioners.

In our sample, reproductive counseling from health care providers was inconsistent, with women primarily reporting experiences of perceived and overt stigma. Experiences of reproductive stigmatization imposed by health care providers have, similarly, been documented by HIV-infected women in other studies (Craft et al., 2007; Kirshenbaum et al., 2004; Sowell & Misener, 1997). For example, HIV-infected women in the Ingram and Hutchinson (2000) study reported feeling stigmatized by their health care providers about pregnancy; some even described their health care providers' strong recommendations toward sterilization, which one of their study participants described as "shutting down the HIV-infected baby machines" (p. 123). Directive advice from health care providers such as reproductive abstinence, abortions, tubal ligations, and other methods of female sterilization can be viewed by women as an overestimation of HIV transmission risks, which ultimately minimizes the trust that women have for their providers. Further, a lack of health care provider support for pregnancy in Southern African American women with HIV, in particular, is reminiscent of historical policies that restricted poor, African American women's reproductive decisions and procreative liberties as a larger institutional attempt to

"dehumanize or control African American women's reproductive lives" (Roberts, 1997, p. 4).

Roberts (1997), in *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*, recounted a policy initiated by Charleston, South Carolina officials in 1989 that led to the criminalization of pregnant women whose prenatal tests revealed crack use. Some women were arrested via teams of police identifying expectant mothers in the most impoverished neighborhoods, and others were arrested in maternity wards hours after giving birth and taken to jail in hand cuffs and leg irons. The majority of these women were poor and African American. Thus, experiences of internalized and overt stigma from health care providers in relation to reproduction has critical implications for employing improved reproductive decision-making models for HIV-infected African American women in clinical settings in order to avoid bearing semblance to historic, disparaging social and medical policies that devalued and restricted a woman's right to reproduce and mother. As Roberts (1997) asserted, "reproductive freedom is a matter of social justice, not individual choice" (p. 6).

Despite reported stigma and dissonance related to reproduction and mothering, a number of women in our study described both their HIV diagnosis and opportunities to mother or re-mother as providing them with a "second chance at life." For instance, several women referred to their HIV diagnosis as motivation to "slow down," and "protect their life" for the sake of their families. Drawing from a newfound sense of purpose, we found that pregnancy and motherhood subsequently provided women in our sample with opportunities and desires to adopt more positive and productive lifestyles while living with HIV. Minimizing the risk of MTCT and increasing the chance of remaining healthy and capable to mother were strong motivators for women to support behavioral change. Having been marginalized by society as a result of injurious behaviors such as drug and alcohol use and criminality, motherhood was expressed as a way for some women in our sample to reshape their social identities and move away from past negative associations and behaviors. Motherhood has also been described as one of few socially valued identities easily obtainable for marginalized women (Barnes & Murphy, 2009; Kirshenbaum et al., 2004). Given the multiplicity of social, psychological, and indirect health benefits of pregnancy, there appears to be considerable endorsement of pregnancy and motherhood observed by the women in our sample.

Limitations

Our study has several limitations, including purposive sampling from a group of women predominately seeking HIV care at health clinics and ASOs in the Southern United States. As a result, findings may not be generalizable to all HIV-infected women, particularly those not seeking HIV care. Due to varying access, women not receiving HIV care may have dissimilar perceptions and knowledge about reproduction and motherhood. Additionally, we cannot ascertain if pregnancy avoidance advice reported by these women was directly due to stigma or a result of health care providers' reliance on outdated clinical recommendations that previously encouraged HIV-infected women to delay pregnancy (CDC, 1985). Thus, future studies should also explore health care providers' knowledge, perceptions, and practices related to preconception counseling for HIV-infected women.

Conclusion

Our study contributes to the growing body of literature related to reproduction and mothering perspectives in HIV-infected African American women of childbearing capacity. Consistent with prior research, women in our study held positive views toward pregnancy and motherhood, in spite of pregnancy avoidance advice and messages. Rather than focusing solely on an HIV-infected woman's potential to infect other individuals, which personifies a person as a disease vector, service providers should offer non-directive advice and exercise respect for patient autonomy when counseling HIV-infected women about reproductive issues. Further research is needed to determine how preconception counseling and shared decision-making models might assist HIV-infected women with their reproductive decisions. Findings additionally lend support for increasing accessibility and availability of integrated HIV care and reproductive services to HIV-infected women to improve the delivery of sexual and reproductive health services and information (Blankenship, Bray, & Merson, 2000; Blankenship, Friedman, Dworkin, & Mantell, 2006).

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Key Considerations

- For HIV-infected women, pregnancy and motherhood can provide a second chance at life and an opportunity to adopt a socially valued identity at a time when women are more receptive to making positive health-related changes.
- Health care providers should emphasize evidence-based recommendations and employ an informed, non-directive decision-making model when offering preconception counseling to HIV-infected women in order to: (a) minimize stigma and personal biases surrounding reproduction, and (b) reduce conception- and pregnancy-related transmission risks to infants and uninfected sexual partners.
- Increased accessibility and availability of integrated HIV care and reproductive services to HIV-infected women is needed to improve the delivery of sexual and reproductive health services and information to HIV-infected women.

Interview Guide Questions

- Please tell me about your history of having children.
- Do you currently have any children? If so, how many?
  - Were your children born before or after your HIV diagnosis?
  - Were you taking ARV drugs?
  - Did you have a C-section?
- If you delivered a baby while HIV positive, please describe what the experience was like.
- Are any of your children living with HIV?
- Please describe what motherhood means to you.
- In what ways, if any, has being HIV positive changed your relationship with your children? [Probe: childrearing practices]
- In what ways, if any, has being HIV positive changed your desire to have a child/additional children?
- How do you feel overall about HIV positive women who plan to have children?
- How important is it to you to have/not have children/more children?
- Please tell me about any advice or opinions that health care providers have given to you about becoming pregnant.
  - Describe how you feel about their advice or opinions.

Figure 1.
Questions used to guide interviews.
Note. ARV = antiretroviral.