

“Throwing the Dice”: Pregnancy Decision-Making Among HIV-Positive Women in Four U.S. Cities

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CONTEXT: Although AIDS-related deaths among U.S. women have decreased, the number of HIV-positive women, especially of reproductive age, has increased. A better understanding of the interaction between HIV and family planning is needed, especially as antiretroviral medications allow HIV-positive women to live longer, healthier lives.

METHODS: Qualitative methods were used to examine pregnancy decision-making among 56 HIV-positive women in four U.S. cities. Biomedical, individual and sociocultural themes were analyzed in groups of women, categorized by their pregnancy experiences and intentions.

RESULTS: Regardless of women's pregnancy experiences or intentions, reproductive decision-making themes included the perceived risk of vertical transmission, which was often overestimated; beliefs about vertical transmission risk reduction strategies; desire for motherhood; stigma; religious values; attitudes of partners and health care providers; and the impact of the mother's health and longevity on the child. Most women who did not want children after their diagnosis cited vertical transmission risk as the reason, and most of these women already had children. Those who became pregnant or desired children after their diagnosis seemed more confident in the efficacy of risk reduction strategies and often did not already have children.

CONCLUSIONS: Future studies may help clarify the relationship between factors that influence pregnancy decision-making among HIV-positive women. HIV-positive and at-risk women of childbearing age may benefit from counseling interventions sensitive to factors that influence infected women's pregnancy decisions.

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Although AIDS-related deaths among U.S. women have decreased, the number of HIV-positive women has increased, and more than half of infections are among black, non-Hispanic women. Given that the majority of HIV-positive women are of reproductive age (13–44 years),¹ it is necessary to understand the interaction between HIV and family planning, especially as antiretroviral medications allow HIV-positive women to live longer, healthier lives.²

Pregnancy decision-making is complicated for HIV-positive women. They must contend with unpredictable symptoms and prognoses, the potential for vertical (mother-to-infant) transmission and often problematic life contexts such as poverty, substance abuse and stigma that may compromise parenting abilities. Few differences have been found between the reproductive beliefs, attitudes and behaviors of HIV-negative and HIV-positive women.³ Infected women are no less likely than other women to become pregnant⁴ and are no more likely to terminate a pregnancy.⁵ The HIV Cost and Services Utilization Study (HCSUS), which examined fertility desires of a large sample of HIV-positive men and women in the United States, revealed that 12% of all infected women and 26% of those younger than 30 conceived after diagnosis. An additional 10% (15% of those younger than 30) had their infection diagnosed during a pregnancy and carried to term.⁶

Women who become pregnant after diagnosis may be

younger, be less educated, have been living with HIV longer and have had more previous pregnancies, miscarriages and abortions than women who do not become pregnant. HIV-positive women in poor health may be as likely to become pregnant as their healthier counterparts, but less likely to continue a pregnancy to term.⁷ In a small convenience sample of rural and urban U.S. women, the serostatus of children born to HIV-infected women was associated with women's future pregnancies.⁸ Data from the HCSUS found that while 29% of HIV-positive women acknowledged a desire for children, 31% of those women did not intend to have children. Women who intended to have children had had fewer previous births than others.⁹

Vertical transmission risk may be an important factor in women's pregnancy decision-making. While the majority of HIV-positive women know their HIV status prior to delivery, a substantial proportion of women and their health care providers do not. Taking prophylactic medication during pregnancy can dramatically reduce, but not eliminate, the risk of vertical transmission. The reported rates of mother-to-child transmission are less than 2% for women who begin treatment early in pregnancy; 12–13% among women who do not initiate treatment until labor, delivery or after birth; and 25% among women who do not receive any preventive treatment.¹⁰

The perceived risk of bearing an HIV-infected child, rather than a woman's HIV status alone, is often associated with

reproductive decision-making.¹¹ However, women's knowledge and perception of vertical transmission risk varies widely.¹² Some women distrust health care providers, believing they may overestimate vertical transmission risk.¹³ Although knowledge of available treatments to reduce vertical transmission may lead women to consider pregnancy, other factors may play an important role in pregnancy decisions.¹⁴

Having or wanting children is generally accepted as the norm for women in the United States,¹⁵ regardless of HIV serostatus.¹⁶ Some circumstances may affect whether or not a woman conforms to this norm, including serious medical conditions, such as HIV, or lack of adequate parenting resources. However, even in the presence of such circumstances, not having a child is often viewed as a norm violation.¹⁷ HIV-positive women may be in a sociocultural double bind, in which their desire for children violates beliefs about "acceptable mothering." Such beliefs may be based on concern regarding the challenges and constraints that some HIV-positive women face, the potential impact on children or the stigma associated with childbearing among infected women.¹⁸ Stigma associated with poverty, ethnic minority status, public assistance, substance abuse and single motherhood may further complicate the dilemma of HIV-positive women contemplating motherhood.¹⁹ Attitudes of peers, partners and family members, as well as religious beliefs, have also been associated with the decision-making of HIV-positive women.²⁰

Few studies have explored how HIV-positive women make childbearing decisions. To address this gap, we used qualitative methods to examine pregnancy decision-making of HIV-positive women in four U.S. cities.

METHODS

Women in the sample were participants in a qualitative study conducted to gain an understanding of issues faced by HIV-positive individuals. Between December 1998 and August 1999, we conducted in-depth interviews with HIV-positive women and men in Los Angeles, Milwaukee, New York and San Francisco. Individuals were eligible to participate if they were HIV-positive, at least 18 years old and able to complete the interview in English. Interview data were used to tailor an intervention trial, which entered the field in the spring of 2000 and was designed to improve coping skills, reduce transmission risk behaviors, and improve medical adherence and other health care behaviors.

Women were recruited from HIV primary care clinics and community-based organizations via provider referrals, word of mouth, or announcements at recruitment sites or in newsletters. Study objectives and procedures were described to potential participants, and consent was obtained. Face-to-face interviews were conducted by experienced interviewers with a master's-level social science education, who received comprehensive training and ongoing supervision. The interviews lasted 2–3 hours and followed a structured schedule of open-ended questions with follow-up probes as needed. Participants were paid \$25 for completing the interview. All interviews were audiotaped and transcribed.

Interviews were designed to elicit in a woman's own words the defining features of her life that might affect health, sexual and drug use behaviors; psychological and practical adaptation to HIV; and preferences for and participation in a behavioral intervention. Questions about women's experiences with reproductive decision-making included the following: "How important is it for you to have/not have (more) children?" "How important is it to your partner to have/not have (more) children?" "What are some of the reasons for the way you feel about this?" "What effect, if any, does HIV have on your desire to have/not have (more) children?" Women were also asked about the number, age, HIV status and current living arrangements of the children they already had.

Analyses were informed by aspects of grounded theory²¹ and were conducted in two phases. In the first phase, transcripts from the entire qualitative phase (including male participants) were reviewed to identify primary coding categories and themes, which were organized into a formal codebook. A coding team of eight people evaluated four transcripts (one from each city) to establish coding consensus and refine coding schema. The team discussed themes that did not fit into this original coding framework and modified the coding when appropriate. They discussed interrater discrepancies until consensus was obtained, and repeated the process until all raters achieved concordance on almost all decisions. Evaluator pairs from the larger team coded 38 additional interviews until a clear saturation was reached for major and minor themes and codes.

The second phase focused on codes and themes associated specifically with pregnancy decision-making. Relevant themes were organized into formal coding grids, and illustrative quotes were extracted from the original transcripts. Analyses were conducted by at least two members of the data analytic team to ensure coding reliability.

We categorized women according to the timing of their diagnosis and reproductive decision-making. Thematic comparisons were made among groups and smaller subgroups where relevant. Certain cross-group comparisons were not possible because of limited data or small group sizes.

RESULTS

Sample Characteristics

The 56 women were 20–55 years old; their mean age was 39.4. The majority were black or Hispanic (Table 1, page 108). Slightly more than half had finished high school or its equivalent, and close to a quarter had taken college courses. Most reported receiving public assistance, and disability was their primary income source. While only 30% of the women were married, the majority were in a relationship; half of all women in the study reported living with a partner.

The women had been living with HIV for an average of 6.5 years (range, 1–17). At the time of diagnosis, 75% were of childbearing age—44 years old or younger. Eighty percent had given birth (Table 1), and these 45 women had had a total of 129 births. Five women reported the death of a child; none of these children had been HIV-infected.

TABLE 1. Percentage distribution of HIV-positive women interviewed about pregnancy decision-making, by selected characteristics, 1998–1999

Characteristic	% (N=56)
City	
Los Angeles	30.4
Milwaukee	17.9
New York	35.7
San Francisco	16.1
Ethnicity	
White	15.1
Hispanic	20.8
Black	60.4
Native American	1.9
Other	1.9
Education	
< high school/GED	40.4
High school/GED	34.6
Some college	23.1
≥ college	1.9
Primary income source	
Own job	16.4
Disability	54.5
Other public assistance	21.8
Family/friend/partner/spousal support	3.6
Other	3.6
Marital status	
Single	39.2
Married	30.4
Divorced/separated/widowed	30.4
Relationship status	
Not in a relationship	16.1
In a relationship/not cohabiting	35.7
In a relationship/cohabiting	48.2
Any birth children	
No	19.6
Yes	80.4
Total	100.0

Note: Percentages are based on those with valid data; missing data did not exceed 10% for any variable.

Among the 44 women with living children, the average number of children was 3.5 (range, 1–8), and the children's mean age was 15.7 years (range, 10 months to 36 years). Forty-four percent of mothers lived with at least one of their children. Two mothers had an HIV-infected child. Sixty-eight percent had borne children prior to diagnosis; three were pregnant at interview.

Of the 56 women sampled, 35 were not pregnant at diagnosis; three of these women subsequently became pregnant, and 32 did not. Twelve women received their HIV diagnosis during pregnancy; seven had a subsequent pregnancy, and five did not. For eight women, the timing of diagnosis and reproductive decision-making was unclear. These women were excluded from the analysis, as was one woman who had had a tubal ligation prior to diagnosis.

Cross-Cutting Themes

Several women across subgroups considered the potential psychological impact of their health and longevity on their children when making pregnancy decisions. Many ex-

pressed concern that if their health failed, their child would grow up without a mother. Because of their parenting beliefs or personal childhood experiences, they wanted a better life for their children than they had had themselves. In the words of one woman:

“I feel I'm the best thing for my children. I'm afraid of dying and my baby has to suffer without me. Not just the fact that the baby might be sick, but I loved my mother with all my heart, the one that raised me...she's the best thing that ever happened in my life. And I'm wondering how my baby will feel if they had to lose me.”—*Pregnant 36-year-old with no children before diagnosis*

A few women spoke of the emotional pain they would feel if they knew they would miss their children's lives because of their failing health or death. They felt strongly that they would not risk having a child if they might not be able to participate fully in their child's life. One woman expressed concerns that her family would be burdened with the care of her children. Another, pregnant at interview, expressed concern that pregnancy itself would pose considerable risk to her health by increasing her viral load and causing a post-pregnancy time lag for viral load reduction.

For some, family planning was independent of HIV status. Many women chose to have children because of a strong desire for motherhood. Some decided against motherhood for non-HIV-related reasons, such as advanced age, satisfaction with their current number of children or doubts about having the capability or resources (e.g., financial, emotional or partner support) to parent adequately. For example, one woman deemed it irresponsible to have a child without the resources needed to create a stable environment:

“It's not an irresponsible thing to have a child. It's an irresponsible thing to have a child without a father, without a decent income, without a place to live and without the ability to take care of this child...while dealing with your own stuff.”—*40-year-old with HIV diagnosed during pregnancy and no children before diagnosis*

For others, family planning was less deliberate. For example, a number of women reported accidental pregnancy due to condom failure or inconsistent condom use. Pregnancy may also occur among couples with a passive prevention approach. One woman reflected this idea when describing how she and her boyfriend, who desired children, were “playing around without condoms.”

Themes Among Women Not Pregnant at HIV Diagnosis

- **No subsequent pregnancy.** Thirty-two women had not been pregnant at the time of diagnosis and reported no pregnancy since that time. Twenty-seven explicitly reported not desiring children, while five women were still contemplating this decision. Of those with no desire for pregnancy after diagnosis, one woman had decided years before her diagnosis that she wanted no children. She had multiple medical problems, which may have precluded her having a healthy pregnancy, and had a long history of psychosocial and substance abuse problems. Women who did not want to have a child cited vertical transmission risk as the pri-

mary reason. Many felt that any possibility of exposing a child to the physical, social and psychological hardships associated with HIV was untenable. Therefore, the decision against childbearing was presented as a foregone conclusion. Women often implied or explicitly described the potential guilt and responsibility they associated with infecting an infant:

“Being that I am infected with the virus, there’s a very good chance that my child can catch it because I have to carry the child nine months. So to avoid it, I just don’t get pregnant....A child shouldn’t have to go through life...having a short life, having the virus because of the mother’s negligence.”—37-year-old with children before diagnosis

For some, pregnancy decision-making seemed driven by their beliefs about HIV treatment and its effect on vertical transmission risk assessment. These assessments were at times predicated on misinformation that caused them to overestimate this risk (e.g., “I knew I’m positive, so I’m quite sure the baby’s going to be positive”). Several women had a more accurate understanding of medication’s benefits while articulating strong feelings that any vertical transmission risk was unacceptable. Some women did not trust the use of antiretroviral medications, which one woman described as “fancy drugs,” to reduce the risk of vertical transmission. One woman, who had a strong desire to have a child, compared using prophylactic medication to gambling:

“I love babies, and I would really like to have one that I could say I raised him all the way myself. Oh, there’s medicines, and there’s this and that. I don’t want to hear that shit. It’s still, it’s the dice.”—36-year-old with children before diagnosis

Women who did not desire children after diagnosis also held strong negative opinions of HIV-positive women who choose to become pregnant. A number of women reported having had a tubal ligation after diagnosis to prevent future pregnancies.

Irrespective of how vertical transmission risk was prioritized in their decision-making, many who did not intend to bear children postdiagnosis spoke of a strong desire for motherhood. Several thought of adoption as a means of satisfying this desire while avoiding vertical transmission risk; one woman was in the process of adopting one of her foster children. The vast majority of women intending not to become pregnant had had children prior to diagnosis; thus, their desire for childbearing may have been satisfied.

Some who did not desire pregnancy spoke of their HIV-positive male partners’ desire to conceive children with them. This evoked strong feelings in the women, who often experienced this as pressure:

“Yeah, he asked me to have children, and I told him no....My husband had passed away...he never asked me for children, our love was sufficient. So, I feel like what is this guy’s problem? He has so many insecurities. He probably feels that he would probably have control over me if I had children.”—41-year-old with children before diagnosis

Women with HIV-negative partners reported a range of partner attitudes toward pregnancy—some partners agreed

that vertical transmission risk was too great, while others wanted to have children with the woman anyway.

The five women who were contemplating pregnancy after their HIV diagnosis differed in meaningful ways from those who did not desire postdiagnosis pregnancy. Risk reduction strategies were major themes in their reproductive decision-making, and they saw prophylactic medications as providing an opportunity to avoid vertical transmission:

“If I get pregnant, I’m going to the doctors anytime I could get there and take the medicines. You don’t have to lose your kids. They can be born with it, but they don’t have to keep it. It depends on the mother.”—41-year-old with children before diagnosis

These women considered a broader range of risk reduction strategies, such as cesarean section, than those decidedly against having children postdiagnosis. Some anticipated that they would try to become pregnant when and if their viral load became undetectable, believing this would decrease the chances of vertical transmission. Several said they were contemplating their decision with input from their health care providers and after consulting educational materials.

Unlike women who did not desire subsequent children, four of the five who were contemplating pregnancy had not had children prior to diagnosis. The one woman who had had children did not live with them.

Each woman who was considering a postdiagnosis pregnancy was in a relationship but not living with her partner. Some partners were actively involved in the decision-making. A few women were contemplating unprotected sex in order to conceive.

• **Subsequent pregnancy.** Three women became pregnant subsequent to diagnosis. Of these, two gave birth to HIV-negative children, and one was pregnant at the time of the interview. Although one pregnancy was reported as unplanned, the degree of planning of the other two was unclear.

The reproductive decision-making these women described was different from that of women who were contemplating a pregnancy. These three women seemed less aware and trusting of risk reduction strategies than their counterparts. The woman who was currently pregnant had limited awareness of medical risk reduction strategies, but stated she might consider them at a later time. Another woman, despite taking zidovudine, overestimated the vertical transmission risk because both she and her partner were HIV-positive. Differences between women who became pregnant and those desiring pregnancy may be due to the nature of their pregnancy planning and preparation. Interpretation of these findings is limited because of small sample size.

Pregnancy intentions may also have been influenced by prediagnosis pregnancy or childbearing experiences. All three of these women had had children prior to diagnosis. However, two had experienced the death of a child. Both women who had already given birth had borne HIV-negative infants. Nonetheless, all three women intended not to become pregnant again, citing vertical transmission risk as too great.

“A child shouldn’t have to go through life...having a short life, having the virus because of the mother’s negligence.”

During pregnancy, each of these women reported feeling stigmatized by the attitudes of health care providers or friends who explicitly questioned why the pregnancy was not being terminated. One woman contemplated abortion, but decided against it because of religious values and her partner's encouragement.

Themes Among Women Pregnant at HIV Diagnosis

Women whose HIV infections were diagnosed during a pregnancy made two sets of decisions—whether to carry the pregnancy to term and whether to become pregnant again. Among the 12 women receiving their diagnosis during a pregnancy, six did not intend to become pregnant again. One woman desired subsequent children. Five women had a subsequent pregnancy.

The initial reaction to an HIV diagnosis during pregnancy often centered on the meaning of the diagnosis to the woman's life, before quickly turning to concern about the potential health impact on the child. All the women carried their pregnancy to term. The pregnancy stage at diagnosis varied and may have influenced the women's decision to maintain the pregnancy (i.e., if the diagnosis was made late in pregnancy, termination may not have been an option). Some women reported continuing their pregnancy despite opposition from others because of strongly held convictions against abortion and a belief that the child would be protected by a "higher power."

- **No subsequent pregnancy.** Like women who were not pregnant at diagnosis, women who were pregnant at diagnosis but did not desire a subsequent pregnancy believed the vertical transmission risk was too great. Most took zidovudine during pregnancy. Many subsequently had tubal ligation to prevent pregnancy and vertical transmission.

Several women did not want to bear more children despite having used zidovudine and given birth to uninfected children. Such women considered themselves to be "fortunate" and "blessed," but said they would not consider a subsequent pregnancy, since they now had an explicit awareness of their HIV-positive status. One woman felt that because she had already been pregnant at diagnosis, her sense of responsibility for vertical transmission risk had been mitigated. However, she believed that it would be wrong to become pregnant after her diagnosis:

"Okay, if I had known that I was positive, I wouldn't have become pregnant with my children. I was fortunate that they were negative....I think that sin is what you know is sin. If I know that I've got something wrong with me and I go out and act with that knowledge, I'm responsible for all of that....You make love to your husband, you nurse your babies. The very things that you do to show your love, that nobody else can do, are the things that could kill them....I think now that I know that, I have no right."—45-year-old with children before diagnosis

Four of the six women with HIV diagnosed during pregnancy who decided against a subsequent pregnancy had had children prior to the diagnosis. In this way, they resembled women who were not pregnant at diagnosis and

decided not to have a subsequent pregnancy. This raises the question of how previous childbearing and motherhood experiences impact postdiagnosis pregnancy decisions.

A woman's diagnosis during pregnancy may complicate her partner's attitude toward pregnancy decision-making. Several women reported disrupted relationships due to a partner's negative reaction to their diagnosis, the pregnancy or both. However, some women reported that their partners, primarily HIV-negative, desired a subsequent pregnancy despite the woman's wish not to conceive. Women who were pregnant at diagnosis reported more precipitous relationship breakups than women who were not pregnant at diagnosis. A partner's prior knowledge of a woman's HIV status may lessen a potentially negative reaction to an infected woman's pregnancy.

One woman who had had children prior to diagnosis wanted to become pregnant again. She took zidovudine upon learning her diagnosis, and her daughter tested HIV-positive at birth, but eventually tested HIV-negative. This woman hoped that the favorable outcome of her pregnancy would bode well for the next. Prophylactic medication was an important risk reduction strategy that she would use again, and she stated that she would become pregnant only if it were again available to her. This woman had four children, who had been returned to her from foster care, and she wanted another child at home because her youngest was starting day care. Children gave her a strong motivation to keep living.

- **Subsequent pregnancy.** Four of the five women pregnant at diagnosis who had a subsequent pregnancy reported taking zidovudine as a vertical transmission risk reduction strategy. Women voiced trust in the medication and seemed to contemplate a wide array of vertical transmission risk reduction strategies. A 22-year-old woman who had no children before diagnosis adhered to her HIV medication regimen in an effort to improve her CD4 and viral load counts as well as to lower her vertical transmission risk. This objective motivated her to persevere with the medication regimen despite its side effects.

Another woman, although encouraged by the outcome of her last pregnancy, seemed more cautious in her current decision-making, given her awareness of transmission risk. Without a strategy to "secure" the outcome, she seemed hesitant to become pregnant again:

"Honest and truly, if they told me that my viral load was undetectable, I'd probably want to have another baby....The Lord has blessed me two times already, thank God, that I don't really want to push it again.... I would like to have another child, but I would like to secure it a bit more."—30-year-old with children before diagnosis

Several women discussed the relationship between an HIV diagnosis during pregnancy and subsequent pregnancy decision-making. They often described the outcome of the pregnancy during which their infection was diagnosed as "a success" if the children were uninfected. Past "success" may be used erroneously to predict a favorable outcome of a future pregnancy.

One woman reported gaining confidence to become pregnant again, only to experience the unfolding reality that her second pregnancy resulted in the birth of an infected infant. The infant tested positive for the virus, but she expected that he would eventually test negative, as this had occurred with the first infant born after her diagnosis:

“That’s what I thought was going to happen....I thought he was just going to lose my antibodies.... It’s not hitting you that your baby has it.”—44-year-old with children before diagnosis

A number of women in this group wanted an opportunity to correct past parenting mistakes, either their own or those they had experienced in childhood:

“My last daughter was also born tox-positive for cocaine, ...and I want to change that.... I want to make sure it doesn’t happen again.”—43-year-old with children before diagnosis

One woman felt stigmatized, particularly by health care providers, during her current and her past pregnancy. This experience was similar to those described by women who had not been pregnant at diagnosis but later became pregnant:

“The fright on [the health care provider’s] face...has stayed within me....It’s very hard for a person to hide their bias.”—36-year-old with no children before diagnosis

She also described pressure she felt from her health care provider to consider abortion. By her account, her health care provider did not mention prophylactic medication. Rather, the message she heard was that any vertical transmission risk should be unacceptable:

“So, the next thing was that there was a 25% probability of passing it to the baby. So, they said that, but they said that like 25% was 100%. First, they ask about abortion, and I said, no....And then they asked me why. My answer was, it doesn’t matter what the reason is.... I’m not going to have an abortion.”

DISCUSSION

Women in this study reflected a variety of pregnancy decision-making experiences. Key considerations included vertical transmission risk assessment, risk reduction strategies and outcomes of previous births that occurred after HIV diagnosis. Desire for motherhood, having children prior to diagnosis, opinions of partners and health care providers, religious values and the perceived capacity to parent successfully regardless of HIV status also emerged from the women’s responses.

The data support earlier findings that HIV status alone is not a key factor in reproductive decision-making among women.²² Women’s attitudes were often associated with personal assessments of vertical transmission potential. That is, those who wanted another pregnancy considered vertical transmission likelihood low, while those who did not want another pregnancy considered it too high. On a related note, and contrary to previous findings, vertical transmission risk was often overestimated. These findings are striking because at the time of these interviews, the effectiveness of prophylactic medication treatment in reducing vertical transmission had been public knowledge for ap-

proximately five years. Moreover, most participants were recruited from HIV primary care settings or had used other health care services that presumably exposed them to this information. Alternatively, health care providers may emphasize vertical transmission risks without fully discussing potential risk reduction strategies or may find it easier to discuss vertical transmission risk than other concerns they have regarding a woman’s capacity to parent; ambivalent women may then become reluctant to explore this topic further.²³ Supporting previous findings,²⁴ some women expressed strong beliefs that if their own health were poor, they would not consider pregnancy; women also were deterred by thoughts that they could become unable to care for a child because of illness, disability or death, and that pregnancy itself could worsen their health.

Consistent with findings by Chen,²⁵ many expressed no intention to have more children after diagnosis, citing vertical transmission risk as the main deterrent. The majority of women in this study had had children prior to diagnosis and did not want more. However, women who had not raised their children or who had had a child die expressed a strong desire for another child, seemingly as a corrective experience. Perhaps those with children prior to diagnosis are more easily influenced by negative messages about HIV and pregnancy because their role as a mother has been fulfilled in the absence of HIV. Those without children before diagnosis seemed less sure about future pregnancy; the desire for motherhood may have more weight for these women.

Many women with children prior to diagnosis stated they would likely carry an unintended pregnancy to term. Similarly, all women in this study who were pregnant at diagnosis carried to term. For these women, strong negative feelings about pregnancy termination seemed to outweigh the considerations that were most salient when HIV-infection during pregnancy was hypothetical. Those who proceed with a pregnancy may be more strongly motivated to consider vertical transmission risk reduction strategies because of the unacceptability of pregnancy termination.

In partial support of previous findings,²⁶ the outcome of postdiagnosis pregnancies influenced subsequent pregnancy intentions for some; having an HIV-negative child gave some women confidence to become pregnant again, while others, relieved that their infant was HIV-negative, did not want to risk a less fortunate outcome in the future. Although these data suggested there were factors differentiating women who did from those who did not have children subsequent to a pregnancy in which they were aware of their HIV status (e.g., having children before diagnosis, having a planned pregnancy, trusting in vertical transmission risk reduction strategies), small sample size prevents us from making more conclusive statements.

Perhaps most important, these data highlight the interplay between sociocultural norms and biomedical considerations in pregnancy decision-making among HIV-positive women. Many women, especially those whose infection was diagnosed during pregnancy or who became

Perhaps most important, these data highlight the interplay between sociocultural norms and biomedical considerations in pregnancy decision-making among HIV-positive women.

pregnant subsequent to diagnosis, discussed conflict between society's overarching doctrine of motherhood as a defining aspect of female identity and adverse judgments concerning HIV-positive women who choose to become pregnant or carry to term. Some may have internalized negative attitudes regarding HIV-positive women having children, or a general negative attitude toward parenthood in the presence of life-threatening illness. Though not evident from these data, such attitudes may be based broadly in ideas regarding race, class, illness and disability, and previous parenting. Or they may be more specifically related to the stigma associated with HIV and to transmission risk behavior, including substance abuse during previous pregnancies. Both illness-specific and non-HIV-related factors related to parenting capacity need to be considered in explorations of women's pregnancy decision-making.

Notably, women in this sample were somewhat older than those in other studies of pregnancy decision-making. While they could discuss current decision-making and previous fertility choices, these results may not be generalizable to younger women.

A number of women reported accidental pregnancy due to condom failure or inconsistent condom use. Although this study inquired about male and female condom use associated with HIV transmission risk reduction, other birth control methods were not assessed. Future studies should more closely examine the complex relationship between pregnancy decision-making and available pregnancy prevention methods. Reports of unintended pregnancies due to condom failure or a more passive approach to pregnancy prevention suggest a need for family planning counseling. The degree to which unintended pregnancies can be attributed to ambivalence, to feelings of decreased control or to other factors is unknown. Active pregnancy decision-making may be less prevalent than a lack of effort to make informed decisions.

CONCLUSION

These data describe how HIV-positive women understand pregnancy decision-making across individual, biomedical and social contexts. The varied and sometimes small subgroup sizes of these qualitative data preclude comparisons possible in controlled quantitative studies. Nonetheless, the data reveal the rich and complex nature of such pregnancy decision-making, which suggests that further examination of this issue among health care providers and HIV-positive and at-risk women is warranted. The misconceptions and misinformation reported suggest directions for family planning education and counseling. Counseling may be complicated by health care provider opinions, expressed directly or indirectly, that may jeopardize a woman's ability to make independent and informed decisions. As women with HIV live longer and healthier lives, better informed women may advocate more strongly for their reproductive rights. Given the clear trend in these data for women who already had children to want no more after diagnosis, HIV-positive or at-risk women who are not moth-

ers may benefit from targeted interventions. Such interventions could address women's desire for motherhood, their health, the health of children they may bear, attitudes and beliefs of significant others in their social network, societal concerns about and possible reactions to HIV-positive women's having children, and their parenting capacities and resources. Thus, the relationships between prior child-bearing, knowledge and beliefs regarding vertical transmission risk reduction strategies, and pregnancy decision-making warrant further systematic assessment. Clinical intervention studies may also help untangle the legitimate concerns of society and policymakers about the ability of some HIV-positive women to parent, given their life circumstances and the stigma surrounding pregnancy for women living with HIV.

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