

REASONS AND JUSTIFICATIONS FOR CONSIDERING PREGNANCY AMONG WOMEN LIVING WITH HIV/AIDS

Karolynn Siegel and Eric W. Schrimshaw
Columbia University

Despite the risks associated with pregnancy, available data suggest that HIV-infected women are no less likely to become pregnant than uninfected women. To understand HIV-infected women's reasons for wanting to have a child, focused interviews were conducted with a predominantly minority sample of 51 HIV-infected women in New York City. They were noted to actively weigh both the potential risks and benefits of their pregnancy decisions. Women reported three major reasons for wanting a child: (1) her husband/boyfriend really wants children, (2) having missed out on raising her other children, and (3) believing that a child would make her feel complete, fulfilled, and happy. Women also reported several justifications that they believed offset the risks of pregnancy, including: (1) other HIV-infected women were having healthy babies, (2) feeling optimistic about having a healthy baby due to the prophylactic effects of AZT (zidovudine), (3) having faith that God will protect the child, (4) being young and "healthy" will prevent transmission, and (5) feeling that she is better able to raise a child now. These findings suggest that to make fully informed pregnancy decisions, women should be encouraged to explore their reasons for wanting pregnancy, as well as discuss the potential risks.

As we enter the third decade of the HIV/AIDS epidemic, women have become one of the fastest growing populations living with the disease in the United States (Center for Disease Control [CDC], 1999). The cumulative number of reported AIDS cases among women has risen dramatically in recent years, from 44,000 in 1993 (CDC, 1994a) to nearly 120,000 by the end of 1999 (CDC, 1999). Further, women account for 23% of all new AIDS cases and 32% of all new HIV infections reported in 1999 (CDC, 1999). About 80% of women with AIDS are 13–44 years of age—within their prime reproductive years. It has been estimated that approximately 7,000 infants are born to HIV-infected women each year, of these 1,000 to 2,000 will be HIV-infected (Davis, Byers, Lindgren, Caldwell, Karon, & Gwinn, 1995). Yet, despite the increasing preva-

lence of women living with HIV/AIDS, little research has addressed their attitudes and concerns about childbearing.

Risks of HIV and Pregnancy

Given the possible risks associated with pregnancy and childbearing while HIV-infected, young women living with HIV/AIDS face difficult reproductive decisions. One significant risk is the transmission of infection to the newborn. Fortunately, when the antiviral drug AZT (zidovudine) is taken on a specific regimen by the mother during the course of the pregnancy and by the infant following birth, it has been found to lower transmission rates to approximately 8% of all births to infected mothers, compared to 25% if untreated (CDC, 1994b; Connor, Sperling, Gelber, Kiselev, Scott, O'Sullivan, VanDyke, Bey, Shearer, Jacobson, Jimenez, O'Neill, Bazin, Delfraissy, Culnane, Coombs, Elkins, Moye, Stratton, & Balsley, 1994). Although newer, more effective treatments for infected individuals are now widely used, their utility in preventing perinatal transmission remains under investigation, and AZT continues to be the recommended treatment for HIV-infected pregnant women (CDC, 1998). This new avenue for the primary prevention of perinatal transmission is a significant and welcomed development; however, it is unclear whether sufficiently early initiation of AZT or adequate adherence to the prescribed regimen (for both mother and infant) are typically achieved outside the structured environment of a clinical trial. Among pregnant, infected women, delays in initiating treatment and

Funding for this research was provided by a supplemental grant from the Office of AIDS Research, through the National Institute for Mental Health (MH50414), Karolynn Siegel, principal investigator.

An earlier abbreviated version of this paper was presented at the annual meeting of the American Psychological Association, Washington, DC, August 2000. The authors would like to thank Helen-Maria Lekas and the reviewers for their helpful comments on an earlier version of this paper.

Address correspondence and reprint requests to Karolynn Siegel, Ph.D., Director, Center for the Psychosocial Study of Health & Illness, Joseph L. Mailman School of Public Health, Columbia University, 100 Haven Avenue Suite 6A, New York, NY 10032. E-mail: ks420@columbia.edu

nonadherence may occur as a result of the pervasive negative attitudes toward AZT (e.g., AZT is toxic and does more harm than good) and its side-effects (Siegel & Gorey, 1997; Siegel, Lekas, Schrimshaw, & Johnson, in press).

An additional reproductive concern for women living with HIV/AIDS is the risk that an uninfected, prospective, biological father will become infected while attempting conception. Although this risk can be obviated through artificial insemination, it is unclear if this would be an affordable or acceptable procedure to most socioeconomically disadvantaged women or couples. When the prospective father is already infected, the risk of possible reinfection with another strain of the virus may also be a concern for both the man and the woman. Infected women considering pregnancy may also worry about the potential negative impact on their own health from the physiological and psychological stresses of pregnancy, although the validity of such concerns remains unclear (Landers, Martinez, & Coyne, 1997). Finally, uncertainty regarding their future health and ability to fulfill the responsibilities of motherhood may also be a concern for infected women contemplating pregnancy.

Despite these acknowledged risks and concerns, research suggests that many HIV-infected women apparently maintain a strong desire to have children. Extant research on the incidence of pregnancy among seropositive women when compared with uninfected women suggests that HIV-infected women are no less likely to become pregnant than uninfected women (Ahluwalia, DeVellis, & Thomas, 1998; Pivnick, Jacobson, Eric, Mulvihill, Hsu, & Drucker, 1991; Sunderland, Minkoff, Handte, Moroso, & Landesman, 1992). Further, although some have contended that HIV-infected women are more likely to choose to terminate their pregnancies than uninfected women (Jemmott & Miller, 1996), studies have consistently failed to find a significant difference in the tendency to have an abortion (Johnstone, Brettle, MacCallum, Mok, Peutherer, & Burns, 1990; Pivnick et al., 1991; Selwyn, Carter, Schoenbaum, Robertson, Klein, & Rogers, 1989; Sunderland et al., 1992). These studies, although representing a much needed first step in understanding the phenomenon of pregnancy among HIV-infected women, provided little insight into the reasons HIV-infected women choose to become pregnant.

Reasons for Pregnancy

Women's pregnancy desires and decisions may be influenced by a large number of psychological, social, and economic factors. Although most of the literature on pregnancy has focused on teen pregnancy or women with fertility problems, some work has examined the pregnancy desires of healthy adult women. One is Gerson's (1985) interviews with 63 primarily White women about their reasons for wanting a child. She demonstrated that both social and personal pressures influenced women's pregnancy decisions. Social pressures for having a child includ-

ed men (husband/boyfriend) encouraging and pressuring the women and perceived social disapproval of childlessness. More personal reasons included women's fears that not having a child would lead to a lonely and desolate old age and the belief that not having a child would mean a loss of an important life experience. It is currently unknown whether the reasons these healthy (i.e., HIV-negative) women offered for wanting a child differ from those of women living with HIV/AIDS.

Few studies have investigated the factors that influence reproductive decisions of HIV-infected women. What research has examined this issue has tended to focus on the structural or demographic correlates or predictors of pregnancy. For example, Kline, Strickler, and Kempf (1995) found that among the 238 seropositive women they studied, multivariate analysis demonstrated that pregnancy was associated with younger age, more years since diagnosis, greater number of children, greater number of miscarriages, having a partner who wanted children, and having a partner with an unknown HIV status. Similarly, in a sample of 403 HIV-infected women studied, Bedimo, Bessinger, and Kissinger (1998) found that only a younger age and a history of sexual assault were significant predictors of pregnancy in multivariate analysis. Although demographic factors such as age, parental history, and disease characteristics, identified as predictors or correlates of pregnancy among HIV-infected women, may provide useful information regarding where to target educational campaigns, they do not offer insights into the reasons that underlie HIV-infected women's desire to have a baby. Furthermore, because demographic factors are not amenable to change, they do not offer the opportunities for intervention that knowledge of reasons for pregnancy may provide (e.g., by identifying and rectifying misinformation that may be the basis for decision-making).

To date, there has been little research into the reasons infected women may desire a child, although some theoretical and descriptive work has begun (Armistead & Forehand, 1995; Jemmott & Miller, 1996; Murphy, Mann, O'Keefe, & Rotheram-Borus, 1998). To date, only two empirical studies have specifically addressed this question. In interviews with 49 HIV-positive women in New York City, Pivnick (1994) identified three major influences on pregnancy. These motives for having children included the desire to have something "of one's own" and the important cultural meaning children had for these women. A third reason was noted among women who already had children but had been separated from them for some period of time (e.g., lost custody due to drugs, homelessness, etc.). These women, who were more likely to desire to become pregnant than women who had not been separated from their children, felt that these children were not fully theirs or believed they could do a better job raising a child now.

Another focus group-based study of 22 HIV-infected women (Sowell & Misener, 1997), half of whom had been pregnant following their HIV-diagnosis, identified several different factors that influenced pregnancy decisions or

current desire to have a child. Among those factors supporting the desire for pregnancy were the women's faith that God would protect the child, past pregnancy experiences (e.g., previously having a healthy uninfected child), and feeling that a baby would make their lives complete. Factors discouraging pregnancy included a lack of awareness that the risk of perinatal transmission could be substantially reduced and concerns about the impact of pregnancy on their own health. The study also suggested that the feelings of family members and sexual partners, including the prospective father, had little impact on women's pregnancy decisions (Sowell & Misener, 1997). While these two studies yielded important insights, the lack of correspondence in the findings suggests the need for additional studies to help clarify the reasons women living with HIV/AIDS may desire to become pregnant.

Many might view HIV-infected women as selfish or deviant for desiring a child or becoming pregnant. Because of this, it is especially important to give voice to these women's own reasons and justifications for their pregnancy. Further, an understanding of the reasons they offer for wanting pregnancy are crucial to gaining insight into the reproductive desires and decisions of HIV-infected women. The present study extends work in this area by investigating not only the reasons women offered for their desire to become pregnant, but also the beliefs these women used to justify these desires. Justifications (Scott & Lyman, 1968) are reasons offered by an individual for why they believe their behavior is acceptable, although the behavior might be viewed as inappropriate or improper by others. These justifications provide insight into these women's own rationale and reasons for desiring a child.

METHOD

Participants

To examine the reasons women offered for becoming pregnant or considering doing so in the future despite living with a life-threatening illness, interviews were conducted with a multi-ethnic sample of 51 HIV-infected women living in New York City. Potential participants were screened over the telephone to determine their eligibility. Women were eligible for inclusion in the study if they: (1) were between 20 and 45 years of age; (2) had tested seropositive for HIV antibodies; (3) resided in the New York City metropolitan area; and 4) if Latina, were Puerto Rican (of any race) and had resided on the mainland for at least four years, or if African American or White, were native born and non-Hispanic; and 5) either were currently pregnant, attempting to become pregnant, or report that they were still open to the possibility of attempting pregnancy sometime in the future. The restriction to only Hispanic women of Puerto Rican descent was made because Puerto Rican women represent the majority of HIV-infected Latinas in New York City, and because inclusion of Latinas of other cultural backgrounds (e.g. Dominicans, Cubans) would

introduce significant cultural variability such that meaningful comparisons could not be made. No restrictions were placed on past drug use or disease stage.

This resulted in a sample of 51 women living with HIV/AIDS. Sixty-five percent were African American, 23% were Puerto Rican, and 12% were non-Hispanic White. The mean age of the sample was 32.5 years ($SD = 5.1$). Forty-three percent of the women had less than a high school education, 18% had graduated high school, 26% had completed some college or professional training, and only 16% had completed an associate's degree or more. Sixty-three percent reported a household income of less than \$15,000 per year. Thirty-one percent were married; 27% were divorced, separated, or widowed; and 41% reported they had never been married. However, many of the unmarried women (71%) lived with a partner or boyfriend. The women represented a number of religious affiliations, including Baptist (29%), Catholic (28%), and other Protestant denominations (14%). Nearly a quarter of the women (22%) reported an "other" religious affiliation (many of whom were Pentecostal), and only three women (6%) reported no religious affiliation. At the time of the interview, 29% of the women were HIV asymptomatic, 26% were HIV symptomatic, and 45% had been diagnosed with AIDS. Twenty-eight percent of the women reported past intravenous drug use.

Most of the women were already mothers (67%) with between one and six children ($M = 2.38$, $SD = 1.41$). Of these, 62% had one or more children currently living with them. Eleven (22%) women were currently pregnant, 9 (18%) were trying to conceive, 6 (12%) were planning to attempt to conceive within the next year, and 25 (49%) were open to the possibility of a future pregnancy. Fifty-one percent of the women (including those currently pregnant) reported having been pregnant since their HIV diagnosis.

Procedure

Women were recruited from a diverse group of community settings, including HIV testing sites, women's health clinics, and HIV service organizations within the New York City metropolitan area. Participants were recruited through advertisements, flyers, and referrals from these organizations. In order to preserve confidentiality, women interested in participating in the research or wanting further information about the study were directed to telephone the research office. Efforts were made to recruit Puerto Rican, African American, and White women from similar sources to avoid selection bias. Women were told that we were interested in their thoughts about being/becoming pregnant while HIV-infected, about their knowledge of the risks, if any, having a baby might pose to themselves or the baby, as well as what they believed were the possible risks and benefits of taking AZT during pregnancy.

Eligible women wishing to participate were scheduled for an interview at the investigators' research offices. After

obtaining informed consent, each woman participated in a focused interview lasting approximately two hours. Interviews were conducted between January 1996 and April 1997, with the majority completed in early 1996—prior to the widespread use of protease inhibitor medications that have greatly improved the health of many HIV-infected individuals. The interviewers were female, Master's-level clinicians experienced in interviewing medically ill individuals. Each participated in approximately 12 hours of training on nondirective interviewing, techniques to inquire or probe for more complete responses, and HIV-specific background information needed for the study (e.g., effectiveness of AZT to prevent perinatal transmission). In addition, interviewers each completed mock interviews. To ensure quality control throughout the data collection period, random interviews conducted by each interviewer were selected, reviewed, and feedback provided. Women were asked if they preferred an interviewer of their same race/ethnicity, and ethnically matched interviewers were provided for all women who expressed such a preference. Puerto Rican participants were interviewed by a bilingual interviewer. Each participant was reimbursed \$25 for the research meeting and travel expenses.

Focused interviews, as conceptualized by Merton, Fiske, and Kendall (1956), were conducted with all study participants. Consistent with this method, interviewers employed an interview guide or outline of topic areas developed by the researchers. The guide was not used as a formal interview schedule, but rather as a conceptual road map that provided points of reference throughout the interview. Interviewers were trained to follow the participants' lead and, when possible, use their comments as a bridge from one topic area to another. The interview guide contained questions about a broad range of topics relevant to women living with HIV/AIDS, including perceived risks and benefits of pregnancy, beliefs about transmission, and attitudes toward AZT during pregnancy. As the data gathering proceeded, the guide was modified to incorporate new insights gained into the phenomenon under investigation. The present analysis focuses on the women's responses to the question, "Can you tell me why you might want to become pregnant despite being HIV-positive?"

Data Analysis

Interviews were audiotaped and transcribed for analysis. Transcripts ranged from 60 to 120 single-spaced pages. The data were then analyzed through a process of thematic content analysis (Krippendorff, 1981). The transcripts were read by the authors to identify themes reflecting the reasons women reported for becoming or wanting to become pregnant. Detailed notes were taken for each participant noting what reasons that individual offered for wanting to become pregnant and other contextual variables that may have influenced her pregnancy desire (e.g., number of children, partner status). The text was analyzed

to examine if the women themselves reported being influenced by their ethnicity, current pregnancy status, or motherhood status. The researchers developed a set of initial codes after each read a random sample of 20 interviews. There was a very high agreement between the two researchers' initial codes (88% agreement) with seven of the eight themes identified by both researchers. Consensus was reached between the two researchers on the final construction of these preliminary codes. The remaining interviews were then coded to determine if the coding scheme developed on the subsample was consistent with the remaining data, and if any additional reasons not identified in earlier interviews were present. No new themes were identified in the full sample of interviews. Inter-rater reliability for the coding was not computed because it was not believed to be meaningful for interviews of this nature (see Morse, 1997). Comparisons were made to examine if the types of reasons or justifications for pregnancy varied by ethnic/racial group, pregnancy status (i.e., currently pregnant or not), and motherhood status (i.e., already have children or not). Finally, quotations were selected by the researchers that they felt best represented the reasons offered by the sample for wanting/becoming pregnant. Direct quotations are presented below, when possible, to better represent the women's own voices.

Many aspects of the design and analysis are consistent with a feminist perspective (e.g., Fine, 1992; Ussher, 1999). For example, central to the present research was the investigators' commitment to illuminating the women's lived experience by giving that experience expression in their own voices. The research also reflected an appreciation of the value and importance of understanding women's lay belief systems in trying to interpret meaningfully and explain their behavior. Finally, the research sought to illustrate the complexity of women's experiences by both illuminating the multiple determinants that shape their behavior and the diverse social contexts in which their actions are embedded.

The qualitative methods and analysis strategy employed in this study were not designed to derive reliable estimates of the true prevalence of the various reasons and beliefs identified as important to pregnancy desires. Because of the nature of the interviews, the content and time devoted to each topic varied considerably from participant to participant, depending on the woman's own salient concerns. Therefore, as in past work employing the same methodology, prevalence statistics have not been calculated. Rather, the goal of the present study was to generate insights, for which qualitative methods are well suited. Each theme reported, however, was found in at least 10 interviewees.

RESULTS

The decision to attempt pregnancy was not one that was made easily or taken lightly by these women. They struggled to weigh their desire to have a (or another) child

against the potential risks involved. All of the women were primarily concerned with the possibility of having an HIV-infected child, and they also expressed fears about their own, and possibly the prospective father's, precarious health and the implications this might have for the child's care in the future. Some also worried that the pregnancy might further compromise their health and accelerate the progression of their disease. Thus, their desire for becoming pregnant was not based on a lack of knowledge or a failure to appreciate the inherent risks. Rather, despite the risks, these women expressed considerable interest in or desire to have a child, and in some cases were already pregnant.

Reasons for Wanting a Baby

Women reported a number of reasons—both personal and social—for wanting to have a baby. The explanations they offered appear similar to those one might hear from healthy women in their reproductive years. When cases were sorted by ethnic/racial group, by currently or not currently pregnant, or by motherhood status, almost none of the reasons were found to be exclusive to one subgroup. The only exception was one reason relevant only to women who had had children previously (see “I missed out on raising my other children” below). The distribution of reasons were similar across groups, although the sample was too small and the distribution of cases across subgroups too skewed to permit a meaningful statistical test of subgroup differences.

My husband/partner really wants children. Many women reported that their desire for a child was strongly influenced by the wishes of a husband or partner. For these women, having a child was a natural goal to pursue within the context of a loving relationship. They did not want HIV/AIDS to deter them from pursuing this goal, especially if their partner desired that they have a child together. For example, when asked why she wanted to have a baby, one woman explained:

Well, the man I'm with, [boyfriend's name], I love him really much, which is kinda weird for me because I never felt this way about somebody so quick and he's like every girl's dream. And um, he has no children, he wants to and it just seems right, you know, to make a baby together. It just seems right. I think between me and him if we made a baby, she would be very pretty. She would have his hair, and she would just be a doll baby, and that would be his mom's first grand[child] and that's like important too. I think he would be a good father, because he's really good with my two [other children].

Other women wanted to provide a child (particularly a son) to a husband who did not yet have children.

Frequently, having a child was viewed as a “gift” that a woman could give her husband or boyfriend. When asked why she wished to have a child, one woman replied:

Because of my husband. Because he wants a son so bad. And I want to be able to give it to him, you know . . . My husband, because he wants a son, you know. I mean I want a baby for him. I do want to have my husband's baby, but I just don't want to have it right now. We just got married. We're going on three months. But I will give him one. But if I get pregnant, yes I'll have the baby, you know, it wouldn't make a difference. [What doesn't make a difference?] Being HIV. It doesn't have anything to do—it doesn't matter. It doesn't matter to him. Before I met him I wouldn't have had no more babies, you know. But since I met him, I want another baby. And being HIV doesn't matter to me, because it doesn't matter to him.

In some cases, it appeared that the husbands or boyfriends exerted a great deal of pressure on the woman to have a baby, causing tension within the relationship. This was because women felt that they would feel guilty and profoundly upset if they acceded to the partner's wishes and the child were to be infected. As one woman commented:

There's a lot of things that goes through your head, both positive and negative. It's like, I started thinking about my husband saying he always wanted a baby, but I still would have that guilt in me. How my baby's gonna be born, how he's gonna feel when he raised up? All these things. [Have you talked to your husband about those feelings?] Yeah, and he say “Well okay, let's stop trying.” But I could see it on he face. He's disappointed. And that makes me feel guilty. Like he really wants it, and I feel like if I stop, it be all right with him, but in another way it would hurt him. And he got the hope high that he want a baby. So, I'm willing to have it, if it comes.

I missed out on raising my other children. Another reason, offered only by women who had previously had children, was that they wanted to have another baby because they felt that they had missed out on some important parts of their child's life because of separations associated with their histories of drug use, homelessness, and prostitution. Typically, during these separations, children had been placed in foster care or with a relative who had assumed legal custody. Some of the women had never regained custody of their children, leaving them feeling childless and wanting a child of their own so that they could enjoy certain experiences of parenthood that they had never had with their other children. However, even those who had regained custody of their child(ren) felt they had missed something very important.

Before I went into recovery my son was removed from my care from the age of six months till two years. And so I missed some very good months and um, yeah, I feel remorseful, because I would have liked to have been with him. After my diagnosis, I didn't think it would be fair to bring another child into this world. But then I thought about it, thinking that I would like to have a baby that I could nurture in the early years. So I thought about it, I'm considering it.

It was like, when he was a baby I didn't have him but two weeks [before he was put in foster care]. So it wasn't like no time at all. So I missed out with him and his brother. All of my kids were taken from me at one point during my drug use. That was my fault, and I understand that now, but I missed out having little babies.

The importance of these lost moments and experiences was so profound that some women felt that their child(ren) were not fully theirs because they had not raised them continuously.

I'm a more responsible person now. I didn't take care of my other four children you know, raising them. I had them for a while when they were maybe up until about five or six years old, and you know that was a really beautiful part of my life and their life. And I would just, you know, I just would like to have a baby that I can like really call mine. Because in some way I don't really call them mine because I didn't really raise them.

A child will enable me to feel complete, fulfilled, and happy. Another reason often cited by the women for wanting to have a child was the belief that it would make them feel complete, fulfilled, and very happy. For those who had already had children, taking care of a newborn was remembered as one of the happiest times in their lives—a happiness they wished to relive. For example,

It's just having a baby it makes me so happy. Taking care of a baby and just the whole process of the whole thing. It makes me so happy. That's like the most happiest times throughout my whole life has been having children. The closeness, just knowing that I'm needed and they depend on me, it's something that makes me feel great. That makes me happy, that they need me. That I have to be there and I have to take care of them and they need to be fed. It fulfills me, my mind, mentally, spiritually, and within my gut, my soul, I feel full. You know it makes me feel that I wasn't just put on this world to be here, I was here for a reason.

For those women who had not yet had a child, having a baby was part of a cherished life dream they greatly wished to fulfill. Many held a romanticized view of family

life, which they felt that having a child would help them realize. For example,

I don't know, it's like you just have this thing in your mind as a child. You want to grow up and get married, go to college, get a house and a car and a dog, and you know, children. It just makes your life complete.

I love kids. I didn't just want one kid. Babies just make you happy. They do. I love babies. I'll babysit anybody's baby for them. Don't even pay me, just let me play with the kid. That's the number one reason.

Others felt that if they could have a child, their lives would feel more complete. Although the women did not speak in terms of the social pressures or the cultural importance of children, some did express that they viewed having children as a natural and important part of being a woman.

I know life would be more complete. I feel like I would be finally complete. There's a missing piece to this puzzle. I have a husband. I have a beautiful apartment. I am starting school next week. I'm going to start counseling, you know, training to be a counselor. My husband's going back to work. I have my cat, a wonderful family. I'd be so complete with a baby in the picture. A child to send to school and just love and nurture.

Well, felt that I would be a complete woman. I would never have experienced a full meaning of womanhood without having a child. Giving birth to a child and nurturing a child. And giving a child my values and teaching it what I know. Leaving something to the world that's hopefully something positive.

Justifications for Wanting a Baby

In addition to their reasons for wanting a child, the women spontaneously expressed a number of beliefs that they felt helped to justify their desire for a baby despite having a life-threatening illness that could be transmitted to the child. Justifications, as originally defined by Scott and Lyman (1968), are reasons offered by an individual for why they believe their behavior is acceptable, although the behavior might be viewed as inappropriate or stigmatized by others. Although we did ask the women what their reasons for wanting to become pregnant were, we did not specifically ask them to justify their desires. Rather, they spontaneously offered these comments in the form of justifications. These justifications appeared to serve a very important role in women's willingness to consider becoming pregnant or having become pregnant. Often these women appeared to be justifying their desire for pregnancy to themselves as well as our interviewers. Women frequently offered multiple justifications. No differences in the justifications offered were noted among the three ethnic/racial groups or between women who were cur-

rently or not currently pregnant or those who already had children and those who did not.

Nearly all of the justifications appeared to address the women's concern about having an HIV-infected child by offering reasons why they believed they could have a healthy baby. Other justifications reflected the women's view that the current prospects for an infected woman having a healthy baby were considerably improved over the past.

Other infected women have had healthy babies. Many of these women reported being personally acquainted with or having heard about other HIV-infected women who had given birth to a healthy baby or whose baby had seroconverted (i.e., was born with HIV antibodies, but never had the virus and now was HIV-negative). This knowledge was very empowering for the women and helped to support their belief that it was possible for infected women, like themselves, to have healthy babies.

Sometimes I think I can't do it, but then I got to have some faith and have some positive attitude that it can be done. Because I know somebody that's HIV-positive. She had a baby. The baby came out big, fat and healthy, but it was HIV-positive. Two months later they took the test again for the baby and it is not positive. Now that baby is bigger and prettier than ever. The baby's fine. I think that could happen to me.

The two [HIV-positive] women I know, their children, the one is two and the other is three. Their children are negative. They were positive, but they're negative now. . . . And well, that's made me feel even a little better to know somebody personally, as opposed to reading about it or seeing a documentary or something.

The lady who told me her baby was okay, that influenced me. She told me, "You gonna be okay," and um, she just mentioned, "I have a baby," and she showed me a picture and she said "My baby's okay." [And why was that so important?] That gave me the inspiration to know that it can happen, that if you do take that chance and get pregnant, that the baby will be okay. It gave me that incentive. I look at it that way. I have a great chance of him not being positive.

The opinions and experiences of other HIV-positive women carried a great deal of weight. In contrast to physicians or family (whom they often suggested had not influenced their desires), other infected women were viewed as peers whose experiences and opinions were more trusted and seen as personally relevant. For example, in response to a query about who had been most influential in her thinking about having a baby, one woman said:

It's just basically like two girlfriends of me that knows that I was thinking—that I talked to them about it. These girls that I go to my clinic with and they pregnant too. They influenced me to keep it.

[Why have their opinions been so important to you?] Because there is no better opinion to take than someone who's actually going through the experience. And they've lived through it. You know, so their opinion means a lot because they're actually going through it and one of them already had one that had HIV converted [became HIV-negative], and she's very optimistic about the second one. So, I think everything is going to be okay for me too.

Not only were women influenced by knowing other HIV-infected women who had healthy children, but those who had themselves given birth to healthy babies since being infected frequently advocated to other HIV-infected women that they too could have a healthy baby. For example,

I know a lot of women out there who are HIV-positive and they want to have a child. And these women, they cry with me in the group how they can't because they'll have an infected baby. You know, and I give them my opinion. Look at me. I did it. You know, there's some place for everything you do in this life. And to me, faith had a lot to do with it. So I suggest they do the same because the decision is up to them. Being positive or not being positive, if you want a child, it makes no sense not to. There are so many things going on now, the medications work. It worked for me. And the decision was solely mine. The same way the decision should be solely theirs.

AZT can help me have a healthy baby. At the time, the recent finding that the risk of vertical transmission (i.e., infection from mother to child) could be substantially reduced through a regimen of maternal and infant use of the antiviral medication AZT was viewed by the women as removing or at least diminishing a significant earlier deterrent to pregnancy. Numerous women expressed that they would never want to have a child suffer with this disease. They felt, however, that because there was now a highly effective, though not perfect, preventive treatment available, the risk of having an infected child was acceptably small now, whereas previously it might not have been. Consequently, they felt it was no longer inappropriate to consider pregnancy.

Before the information about AZT came out, I saw the risk as being 25% to 30%, and it was well absolutely not, that's way too big a risk. But when all of this information about AZT became available, both my husband and I talked about it and we were really excited about it and thought, humm, well, a 10% or 8% risk, maybe we can do that and just pray that we're not in that 10%, and sort of stay inclined to open up the potential of having a baby.

Until they came out with the possibility of administering AZT while a woman is pregnant, I had already decided I was not going to have a child. I was con-

sidering attempting to adopt. I was preparing to have a tubal ligation. But they kept telling me here at the gyn clinic that I was too young, and why would I even consider it. But once I found out about the results—the possible results, I had changed my mind and I said okay. Now I'm willing to try. Once I heard about the results I said well now I can attempt to have my own child rather than adopt.

I have faith in God. Several of the women who were religious used their faith not only in coping with the everyday stresses of the illness, but also in helping to direct their lives. Thus, it is not surprising that many offered their faith in God as a strong influence on their pregnancy decision-making. These women often discounted the risks of vertical transmission, believing that God would protect the child from being HIV-infected.

Now I want to have a child because I know, I have faith in God, you know what I'm saying; that I was blessed that my last baby didn't come out positive. I have it in my heart that I know I'm going to have a healthy baby, so I'm trying not to think negative. I want to think positive. But if it happens [the baby is infected], I'm still going to love it just the same.

When the time comes for me to get pregnant, I believe that I will get pregnant. And I believe that the child will be born not infected. I mean that's just something—like I was saying about God. I mean, God is sovereign. He does what he wants to do. I know that even though I've done what I've done to get this [HIV], I believe that he will be just, and not let my child become HIV-positive. I really do. And I just feel that so strongly that I'm just gonna leave it in fate and see what happens.

Today I have faith that I am going to live. I know that God is going to bless me with a child. I know my child ain't going to suffer and he's going to have or he or she is going to have the good things I never had. He won't suffer with the HIV, with this disease.

Others entirely relinquished control over their pregnancy to God. These women believed that God would not allow them to become pregnant if it was wrong or if it would result in a sick child. To these women, babies were viewed as gifts from God, provided to women who were doing “the right thing”:

I didn't know what I should do. So I decided to take it to—to God in prayer. And I said “God, if it's your will, I will get pregnant. And if I don't, then I will accept that.” And after about a month after I took this in prayer, I was pregnant after 15 years of nothing. So that made me think that I was, you know, doing the right thing.

I'll leave it in God's hands. I mean, you know, if it wasn't meant for me to get pregnant, God wouldn't

put it there. Evidently it was meant for me to be pregnant. I strongly believe in God, I believe that. And I know He's a healer and I believe He can heal me from this, if I do the right thing.

The belief that whether they would have a healthy child, or even become pregnant, was in God's hands, allowed some women to believe it was all right to forego using condoms to prevent pregnancy, or to take AZT to help prevent transmission to the baby if they became pregnant. Their belief that God's wishes would be served by whatever happened enabled women to relinquish control of any pregnancy decisions and shift responsibility for whether they became pregnant and the outcome of that pregnancy to God.

I am still healthy and young. Contrary to current medical views, some women felt that the chances of having a healthy child could be even further increased if they stayed in good health during pregnancy and took care of themselves. Many believed that if they were going to have a child, they should do it while they were still young and “healthy.” That is, these women believed that as their disease progressed (T-cells lowering, viral load increasing) the risks of transmission of the virus to the baby would increase. They also believed that older age in general was associated with more risks of having an unhealthy child.

Something in the back of my mind keeps telling me you're 30 years old, your biological clock is ticking, and my T-cell count is still high. I'm in the 1,100 range. So I don't want to wait until I get much older and my body gets weaker and then the chances of transmitting it to the baby would be greater, so I figure now is the time if I'm going to do it.

My T-cell count is so high, and I haven't experienced any of the opportunistic diseases. So I feel that the chance would be greater for me to have a healthy child, because I'm not so sickly and my body is healthy. So I figure my chances are much more greater to have a healthy child now.

There's like a time clock clicking in my head. Like I may be physically able to have this child now, but who's to say in six months from now, everything could turn around and I won't be able to carry the baby full term or have a healthy child. So that's another thing too. The clock is ticking, so if I'm going to do something, it's best that I do it now and go ahead with it.

I am better able to raise a child now. A number of women felt that because they had stopped using drugs (often in response to their HIV diagnosis) they were now, in some cases for the first time in their adult lives, responsible enough to care for a child. Ironically, while some had never considered motherhood before their diagnosis because of their lifestyle, they now felt it appropriate for

them to contemplate that possibility. Often, those who wanted to have another child because of missing out on some part of their children's lives justified that desire by arguing that they felt that they were far better able to care for a child now than they had been earlier.

Because of my active addiction, I missed a lot of my three children growing up. But this would give me a chance to be able, because I'm clean now, to raise this one fully, without being under the influence of anything.

I want a baby so bad. I think that at this time in my life, I've stopped doing drugs, I've stopped doing alcohol. I've really turned my life around. I did a 360-degree with my life. I've educated myself and I help others today. I think that that's one of the things that I really want.

I made a lot of mistakes when I had my son before. I don't know, it would be like to make up or try to do it right this time maybe. Maybe in a sense it would be for that too. To try to get it right this time. Do things differently.

Others were in a stable relationship with a partner for the first time in many years. These changes led them to perceive their situation as one that would provide suitable circumstances for contemplating having a child.

Well first of all, with my children, I was never married. If I were to get pregnant, this would be my first child that's not born out of wedlock. And I'm in a much healthier, happy relationship. This time I would have someone that would help me raise my children, because I raised the other three by myself.

I've gotten my life together. I have a great relationship with my boyfriend. I've always wanted to be a mother, but I was just too wrapped up in myself and hanging out and partying to ever consider it. I also like the fact of looking at a little me. Just the thought of having a child makes me smile. The joy of having someone that is mine, all mine, you know. This came from me. This is my baby, and just having those little things like "Mommie, I'm home" or kisses and those little "Mommie, I love you" and stuff like that. I've missed all these years, being so selfish, wrapped in myself. Now that life is all behind me, it's something that I really would like to enjoy before I leave this earth.

DISCUSSION

The present study provides additional insights into the psychosocial factors associated with HIV-infected women's desire to become pregnant despite their illness. Although the choice to attempt conception while living with HIV/AIDS has been viewed by others as short-sighted or selfish, these desires and decisions need to be understood from the perspective of the women making this choice.

These women recognized that the decision to bear a child while infected carried risks for the child, as well as for themselves and their partners. However, they also felt a strong desire for a child.

Reasons and Justifications for Wanting a Child

Some of the reasons the women offered for desiring a child were similar to those that might be found among their healthier peers in their reproductive years, such as the wanting to satisfy the wishes of husbands or partners or the belief that a child would bring a sense of fulfillment and completeness (Gerson, 1985). A number of the reasons identified among these HIV-infected women were also quite similar to those reported in an earlier study of women's feelings about pregnancy following breast cancer treatment (Siegel, Gorey, & Gluhoski, 1997). Women with breast cancer also reported both that their desire for a child was influenced by their husband's wishes and that having a child was part of a cherished life dream they wished to realize and that would fulfill them in a unique way. This suggests that women, regardless of their health or illness, may hold similar reasons for wanting a child.

The present findings are also consistent with prior work on pregnancy among HIV-infected women. Consistent with Pivnick (1994), we found that women who had been separated from their children, even temporarily, wanted another chance to raise a child so that they could fully experience the joys of motherhood and parent this new child better than they had their previous children. Like Sowell and Misener (1997), we found that some HIV-infected women reported that they were placing their faith in God to protect any child they might have against becoming infected. They also found, as we did, that women felt that a child would fulfill them and make their lives more complete. However, while Sowell and Misener (1997) explicitly remarked that husbands and family had little influence on women's pregnancy decisions, our data confirmed Kline and colleagues' (1995) finding on the importance of a partner's wishes for a child. However, consistent with Sowell and Misener (1997), family (i.e., parents and siblings) and physicians were found to have little influence in the present study. Thus, the great similarity of the present findings to previous work lends greater confidence to the validity of these findings.

In addition to reporting their reasons for wanting to have a child, the women also frequently offered "justifications" (Scott & Lyman, 1968) or explanations for why they believed a pregnancy was an acceptable and responsible choice despite their illness. Although women were never asked to justify their desires, these reasons were spontaneously offered for why pregnancy was an acceptable choice. Perhaps, because these women were very aware of the public attitudes against HIV-infected women becoming pregnant, these women felt the need or had previously needed to defend their desires. However, it appeared that these women were using these justifications to justify

their desires to *themselves* as well. These justifications also appeared to be very important in enabling the women to feel more comfortable with their desire to have a baby. Unlike the reasons for desiring a child, many of these justifications were specific to the HIV/AIDS context. The overarching theme of the majority of the justifications offered was to provide explanations for why the women believed they could now have a healthy baby (e.g., God would protect the baby, other women have had healthy babies, I am healthy so I am more likely to have a healthy baby, AZT can help me have a healthy baby).

One previously unreported justification offered for becoming pregnant or contemplating pregnancy stemmed from the recent finding that an antiviral medication regimen (AZT) reduced the risk of mother-to-child transmission of infection. Many women felt that this reduction in transmission rates was sufficiently low to make pregnancy an acceptable risk and was justification enough to consider pregnancy. It should be noted, however, that while the women viewed the finding that AZT could significantly reduce the risk of perinatal transmission as a very positive development, many continued to have negative attitudes about the side-effects of AZT and the risks associated with its toxicity. Others were concerned about the danger exposure to AZT posed for the baby or were uncertain if it would benefit the child. Indeed, a number of women felt that the 25% risk of transmission found among women not using the AZT regimen was sufficiently favorable odds for them to risk pregnancy without taking the antiviral regimen.

Consistent with earlier work on health behaviors and health decision-making, the present study suggests that the experiences and beliefs of other HIV-infected women may be very important in choosing to become pregnant. Previous work has suggested that peer beliefs and experiences may more strongly influence health behaviors and attitudes—such as those associated with medication adherence—than professional advice or recommendations (Siegel & Gorey, 1997; Siegel, Schrimshaw, & Raveis, 2000). The finding that discussions with other HIV-infected women who have had a healthy child were very important to other women's pregnancy desires suggests that beliefs about pregnancy (and its risks and benefits) are socially transmitted. Further evidence for the influence of interpersonal factors on attitudes toward childbearing exists in the women's reports of wishing to please their husbands/partners as one reason for desiring to become pregnant. Future research should explore more systematically the role of other possible interpersonal sources of influence on pregnancy decision-making, such as family, peers, and one's health care providers.

Of particular interest is the function that religious faith played in these women's reproductive decisions. Weighing the desire for a child against the risks of pregnancy left many women with great uncertainty as to what reproductive decision to make. For some, the responsibility for their desires and actions was reduced or eliminated by relinquishing to God control over both whether they

become pregnant and the consequences for the child's health. By placing faith in God to protect the unborn child and to only allow pregnancy to occur if God felt it was the right thing to happen, the women reduced their conflict about becoming pregnant. This belief in the protective power of faith in some cases also diminished the motivation to use contraception, as well as the perceived need to take AZT to prevent transmission of the virus to the unborn child. Although religious faith was found to greatly influence many women on their contraception and pregnancy desires, its significance within other more religiously diverse samples must be explored. The heavily Baptist, Pentecostal, and Catholic sample obtained here may exhibit a greater faith in the healing and protective power of God than women affiliated with other religious denominations. Clearly the role of religiosity and/or religious denomination on pregnancy decisions as well as other health behaviors merits further exploration.

Perhaps as notable as the reasons and justifications offered for considering becoming pregnant were those that were not offered. For example, it was expected that like breast cancer survivors (Siegel et al., 1997), HIV-infected women would report wanting a child because they wanted to feel "normal" and be involved in the same developmental tasks (child-rearing) as their peers. While a couple of women suggested this as part of their motivation for wanting a baby, this was not a frequent or salient theme among the study sample. Another reason that was anticipated but not identified within the interviews was wanting a child in order to have someone who offered them unconditional love and who depended on them. Finally, in contrast to expectations, we found no differences in the nature of the reasons and justifications offered by currently pregnant women and those who felt they might desire to become pregnant in the future. Nor were any ethnic/racial differences observed or differences with respect to whether or not the women already had had any children (with the above noted exception). However, due to the small sample of White women and of currently pregnant women, the assertion that no differences exist cannot be made with certainty.

Limitations

A number of potential limitations of the present study must be acknowledged. Given that women had to self-refer into the study, it is possible that the study participants were more open about their HIV status than those who did not participate. Thus, the present sample may represent a selected sample of the population of younger HIV-infected women who experience less shame or feelings of stigmatization. Such women may feel less constrained than others about social attitudes toward infected women becoming pregnant. Further, while the women's reports offer insight into factors that may influence their decision to become pregnant, future longitudinal and quantitative research will be required to link these reasons

and justifications to actual pregnancy outcomes. Because the sample was restricted to women who were currently pregnant, attempting to become pregnant, or open to the future possibility of becoming pregnant, the study does not shed light on the perceived barriers and deterrents to pregnancy that may counterbalance women's reasons for desiring to become pregnant and their justifications for such a choice. Finally, recent developments in antiviral medications, such as the widespread use of protease inhibitors, have taken place since data collection. The potential implications this may have for women's consideration of pregnancy are currently unknown and need further research.

Implications

The findings have a number of implications for supportive interventions with HIV-infected women. In cases where the husband or partner's desire for a child is the principal motive, women should be helped to explore the stability of the relationship and the likely availability of the prospective father to help in the care and raising of the child. Women should also be encouraged to explore the strength of their own desire for a child independent of the partner and how they would feel if they had a child to please the partner and he subsequently left the relationship. Further, previous research suggested that many HIV-infected women feel that because of their illness they have very restricted opportunities for a relationship with a man. Thus, they are often willing to "settle" for a relationship that is unsatisfying in a number of ways. Women need to be encouraged to examine if they are considering having a baby to please their partner out of a fear of losing him if they do not accede to his wishes. Their emotional and sometimes financial dependence on their partner could obviously make them fearful of denying the partner's wishes even when they may not share the strong desire for a child.

With effective treatments, a supportive social network, and adequate information regarding the potential risks of pregnancy, HIV-infected women can make informed decisions regarding pregnancy, take preventative steps to reduce possible transmission to the child, and likely give birth to a healthy baby. Indeed, with current treatments available, this is probable. However, to make informed decisions women must be aware not only of the risks associated with pregnancy, but also must have inaccurate information or beliefs dispelled. The justifications offered by these women suggest a number of misconceptions, which may need to be directly challenged in future educational efforts. For example, the belief that being young or "healthy" will help reduce the risk of HIV transmission is unfounded. However, through promotion of accurate knowledge about risks and benefits of pregnancy, women living with HIV/AIDS may be empowered to make confident and fully informed decisions regarding pregnancy.

Initial submission: February 7, 2000

Initial acceptance: June 15, 2000

Final acceptance: November 17, 2000

REFERENCES

- Ahluwalia, I. B., DeVellis, R. F., & Thomas, J. C. (1998). Reproductive decisions of women at risk for acquiring HIV infection. *AIDS Education and Prevention, 10*, 90-97.
- Armistead, L., & Forehand, R. (1995). For whom the bell tolls: Parenting decisions and challenges faced by mothers who are HIV seropositive. *Clinical Psychology: Science and Practice, 2*, 239-250.
- Bedimo, A. L., Bessinger, R., & Kissinger, P. (1998). Reproductive choices among HIV-positive women. *Social Science and Medicine, 46*, 171-179.
- Centers for Disease Control and Prevention. (1994a). *HIV/AIDS surveillance report, 5*, 1-33.
- Centers for Disease Control and Prevention. (1994b). Zidovudine for the prevention of HIV transmission from mother to infant. *Morbidity and Mortality Weekly Report, 43*, 285-287.
- Centers for Disease Control and Prevention. (1996). *HIV/AIDS surveillance report, 8*, 1-40.
- Centers for Disease Control and Prevention. (1998, January 30). Public Health Service Task Force recommendations for the use of antiretroviral drugs in pregnant women infected with HIV-1 for maternal health and for reducing perinatal HIV-1 transmission in the United States. *Morbidity and Mortality Weekly Report, 47*(RR-2), 1030.
- Centers for Disease Control and Prevention. (1999). *HIV/AIDS Surveillance Report, 11*, 1-45.
- Connor, E. M., Sperling, R. S., Gelber, R., Kiselev, P., Scott, G., O'Sullivan, M. J., VanDyke, R., Bey, M., Shearer, W., Jacobson, R. L., Jimenez, E., O'Neill, E., Bazin, B., Delfraissy, J-F, Culnane, M., Coombs, R., Elkins, M., Moye, J., Stratton, P., & Balsley, J. (1994). Reduction of maternal-infant transmission of human immunodeficiency virus type I with zidovudine treatment. *New England Journal of Medicine, 331*, 1173-1180.
- Davis, S. F., Byers, R. H., Lindgren, M. L., Caldwell, M. B., Karon, J. M., & Gwinn, M. (1995). Prevalence and incidence of vertically acquired HIV infection in the United States. *Journal of the American Medical Association, 274*, 952-955.
- Fine, M. (1992). *Disruptive voices: The possibilities of feminist research*. Ann Arbor, MI: University of Michigan Press.
- Gerson, K. (1985). *Hard choices: How women decide about work, career, and motherhood*. Berkeley, CA: University of California Press.
- Jemmott, J. B., & Miller, S. (1996). Women's reproductive decisions in the context of HIV infection. In A. O'Leary & L. S. Jemmott (Eds.), *Women and AIDS: Coping and care* (pp. 167-184). New York: Plenum.
- Johnstone, F. D., Brettler, R. P., MacCallum, L. R., Mok, J., Peutherer, J. F., & Burns, S. (1990). Women's knowledge of their HIV antibody state: Its effect on their decision whether to continue the pregnancy. *British Medical Journal, 300*, 23-24.

- Kline, A., Strickler, J., & Kempf, J. (1995). Factors associated with pregnancy and pregnancy resolution in HIV seropositive women. *Social Science and Medicine*, 40, 1539–1547.
- Landers, D. V., Martinez, T. B., & Coyne, B. A. (1997). Immunology of HIV and pregnancy: The effects of each on the other. *Obstetrics & Gynecology Clinics of North America*, 24, 821–831.
- Merton, R. K., Fiske, M., & Kendall, P. (1956). *The focused interview*. Glencoe, IL: Free Press.
- Morse, J. M. (1997). "Perfectly healthy, but dead": The myth of inter-rater reliability. *Qualitative Health Research*, 7, 445–447.
- Murphy, D. A., Mann, T., O'Keefe, Z., & Rotheram-Borus, M. J. (1998). Number of pregnancies, outcome expectancies, and social norms among HIV-infected young women. *Health Psychology*, 17, 470–475.
- Pivnick, A. (1994). Loss and regeneration: Influences on the reproductive decisions of HIV positive, drug-using women. *Medical Anthropology*, 16, 39–62.
- Pivnick, A., Jacobson, A., Eric, K., Mulvihill, M., Hsu, M. A., & Drucker, E. (1991). Reproductive decisions among HIV-infected, drug-using women: The importance of mother-child coresidence. *Medical Anthropology Quarterly*, 5, 153–169.
- Scott, M. B., & Lyman, S. M. (1968). Accounts. *American Sociological Review*, 33, 46–62.
- Selwyn, P. A., Carter, R. J., Schoenbaum, E. E., Robertson, V. J., Klein, R. S., & Rogers, M. F. (1989). Knowledge of HIV antibody status and decisions to continue or terminate pregnancy among intravenous drug users. *Journal of the American Medical Association*, 261, 3567–3571.
- Siegel, K., & Gorey, E. (1997). HIV-infected women: Barriers to AZT use. *Social Science and Medicine*, 45, 15–22.
- Siegel, K., Gorey, E., & Gluhoski, V. (1997). Pregnancy decision making among women previously treated for breast cancer. *Journal of Psychosocial Oncology*, 15, 27–42.
- Siegel, K., Lekas, M-L., Schrimshaw, E. W., & Johnson J. K. (in press). Factors associated with HIV-infected women's use or intention to use AZT during pregnancy. *AIDS Education and Prevention*.
- Siegel, K., Schrimshaw, E. W., & Raveis, V. H. (2000). Accounts for non-adherence to antiviral combination therapies among older HIV-infected adults. *Psychology, Health & Medicine*, 5, 33–46.
- Sowell, R. L., & Misener, T. R. (1997). Decisions to have a baby by HIV-infected women. *Western Journal of Nursing Research*, 19, 56–70.
- Sunderland, A., Minkoff, H. L., Handte, J., Moroso, G., & Landesman, S. (1992). The impact of human immunodeficiency virus serostatus on reproductive decisions of women. *Obstetrics & Gynecology*, 79, 1027–1031.
- Ussher, J. M. (1999). Feminist approaches to qualitative health research. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 98–114). London: Sage.