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This study examined how women's relationship with their primary health care provider (PHP) and their perceptions about how effective their PHPs believe zidovudine (AZT) to be in decreasing perinatal transmission related to women's AZT beliefs and intentions. It used a cross-sectional design to collect data from 59 HIV-infected African American women. Almost half the women (45%) had given birth since HIV diagnosis. Most of the babies born to HIV-infected mothers (87%) were seronegative. Data analysis with Pearson's r indicated that the quality of the women's relationship with their PHP was positively correlated to how important the PHP would be in decision making related to AZT therapy. Significant positive correlation was observed between women's perceptions about how effective their PHPs believed AZT to be in decreasing perinatal HIV transmission and the women's own beliefs about AZT, their intent to take AZT if pregnant, and intent to give AZT to a newborn.

Health Care Providers' Influence on HIV-Infected Women's Beliefs and Intentions Related to AZT Therapy

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Despite efforts to prevent the spread of HIV infection, the number of new cases of HIV continues to spiral upward. Women of reproductive age represent a disproportionately large number of individuals being diagnosed with HIV/AIDS

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(Centers for Disease Control [CDC], 1998b). This situation has serious consequences not only for women who become HIV infected but for their babies if these women become pregnant. It is estimated that without treatment, 15% to 30% of babies born to HIV-infected mothers will have HIV (Anastos, Denenberg, & Solomon, 1998). Recent research has shown that treatment of mothers during pregnancy with zidovudine (AZT) can significantly decrease the transmission of HIV from mother to baby (CDC, 1994; Simonds et al., 1998). The ability to significantly decrease the perinatal transmission of HIV offers one of the few real successes in HIV prevention.

Although there is evidence that antiretroviral drug therapy (i.e., AZT) can decrease the chances of perinatal transmission of HIV, many women do not seek or adhere to such therapy during pregnancy. Previous research indicates a number of factors that may influence HIV-infected women's willingness to take antiretroviral drugs. These factors include inadequate or incorrect information about antiretroviral therapy, a belief that AZT is not effective or may have adverse side effects or be harmful to their babies, and the lack of support for drug therapy among peers (Misener & Sowell, 1998; Smith, Rapkin, Morrison, & Kammerman, 1997; Sowell & Misener, 1996; Sowell, Seals, et al., 1996; Williams, 1997). If women lack accurate information concerning AZT therapy, health care professionals have a unique opportunity to intervene with appropriate education that increases the likelihood of women accepting and adhering to AZT therapy.

Health care professionals should be one of the most important sources of treatment information for women with HIV infection. Past negative experiences with the health care system and/or a specific health care provider may cause women to be suspicious or mistrust health care professionals (Austin & Dodge, 1992; Gentry, 1993; Mitchell, Tucker, Loftman, & Williams, 1992; Sowell, Seals, et al., 1996). HIV-infected women who do not have a trusting relationship with their health care provider may be less likely to accept advice about treatment options than women who trust their health care provider

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(Rheiner, 1995). The status of the health care provider as a treatment expert may overshadow any negative feelings a woman has about the health care provider, resulting in a willingness to accept prescribed antiretroviral therapies. To date, there is a paucity of data as to how HIV-infected women's willingness to accept and adhere to AZT therapy is influenced by the relationship that exists between the woman and her health care provider.

PURPOSE AND SIGNIFICANCE

The purpose of this study was to examine how women's relationships with their primary health provider (PHP) related to their beliefs and intentions concerning AZT therapy during pregnancy. Specifically, did women's relationships with their PHP influence the women's evaluation of the effectiveness of AZT in preventing perinatal transmission of HIV, their intent to take AZT if becoming pregnant, and their intent to give AZT to their newborns for a recommended period of time? In addition, the study sought to determine if there was a significant relationship between women's perceptions of how positively their PHP viewed AZT therapy during pregnancy and women's evaluation of effectiveness of AZT therapy, their intent to take AZT if becoming pregnant, and their intent to give AZT to their babies after birth.

A search of the social science and nursing literature revealed no other studies that examined the potential influence of the relationship between HIV-infected women and their PHP on their beliefs about AZT therapy during pregnancy and their intent to take AZT if becoming pregnant. Furthermore, only one study could be found that examined the relationship between physicians' evaluation of AZT and women's willingness to take AZT during pregnancy (Seals, Hennessey, & Sowell, 1996). Seals and associates, using a series of situational vignettes related to acceptance and adherence to AZT, found a negative relationship between physician doubt about AZT therapy during pregnancy and women's willingness to initiate therapy. Findings of the Seals, Hennessey, et al. (1996) study suggest that health care professionals may play an important role in women's decisions to take or not take AZT during pregnancy. The current study goes beyond the Seals, Hennessey, et al. (1996) study in several ways. First, the study expands the

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definition of PHP to include nurses who provide much of the care to HIV-infected women. Second, it focuses outcome measures on women's actual evaluation of the effectiveness and intent to take AZT. Third, this study examines the correlation between how positively women viewed their relationship with their PHP and the women's attitudes and behaviors related to AZT therapy.

BACKGROUND

As of December 1998, the Centers for Disease Control and Prevention (CDC, 1998b) reported that 109,311 women in the United States have been diagnosed with AIDS. Minority women represent a disproportionate number of cases in women, with 80,652 African American women having been diagnosed with HIV/AIDS (CDC, 1998b). Although HIV infection is not monitored by all states, data from 25 states that report names of HIV-infected individuals as well as those who have AIDS support that a greater percentage of women (28% vs. 17%) and African Americans (57% vs. 45%) are infected with HIV than was previously indicated (CDC, 1998b).

In contrast to the first cases of HIV/AIDS identified in urban men, women with HIV/AIDS often live outside of metropolitan centers and in the South (CDC, 1998a; Lam & Lui, 1994). In fact, the increased number of HIV/AIDS cases among women in the South represents one of the largest in the United States (CDC, 1998b). A review of national HIV/AIDS statistics reveals that Georgia and South Carolina rank 9th and 10th respectively in AIDS cases among women. As of September 1998, in Georgia, where only AIDS cases are reported, there have been 2,976 cases of AIDS diagnosed in women (Department of Human Resources, 1998). In South Carolina, where both HIV infection and AIDS cases are reported, there have been 3,532 cases of HIV/AIDS (Department of Health and Environmental Control, 1998).

The majority of women diagnosed with HIV/AIDS are of reproductive age (16 to 44 years) and a growing number of these women are being infected through heterosexual activities (CDC, 1998b). Such trends mean that HIV infection is not only a growing concern for women but poses a potential risk to children born to HIV-infected mothers. There have been 8,280 cases of pediatric AIDS (CDC, 1998b), and it has been

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estimated that more than 7,000 infants are born to mothers who are HIV infected each year (CDC, 1994). Almost all newly diagnosed cases of AIDS among children in the United States can be attributed to perinatal transmission of HIV.

AZT was the first and continues to be one of the most widely used antiretrovirals to combat HIV infection (Aboulker & Swart, 1993; Vella et al., 1994; Volberding et al., 1989). Although not initially recommended for use in pregnant women, AZT has become the treatment of choice for preventing perinatal transmission of HIV. In February 1994, the National Institutes of Health interrupted a clinical trial (ACTG 076) testing the efficacy of AZT during pregnancy to decrease vertical transmission of HIV. Women receiving the ACTG 076 treatment protocol took AZT during their pregnancy and administered a pediatric dose of AZT to their newborns for 6 weeks following birth. The study was discontinued when a dramatic difference in perinatal transmission was observed in the treatment group (8.3% transmission rate) as compared with the control group (25.5% transmission rate) (CDC, 1994). Based on the ACTG 076 study, the CDC issued recommendations for HIV counseling and voluntary testing of pregnant women (CDC, 1995). However, interruption of ACTG 076 left many unanswered questions concerning AZT therapy that continue to fuel debate among scientists, ethicists, and consumer advocacy groups. Central to this debate are issues related to the benefit and safety of AZT therapy and the ethics of mandatory HIV testing of pregnant women and newborns with subsequent enforced antiretroviral therapy (Ayers, Clive, Tucker, Hajian, & De Miranda, 1996; Dumois, 1995; Institute for Family-Centered Care, 1994).

Although AZT therapy has been shown to decrease perinatal transmission of HIV and it has become the standard of care for HIV-infected pregnant women, there is evidence that many women do not take AZT during pregnancy (National Institute of Allergy and Infectious Diseases, 1994; Sowell & Misener, 1996). Some women have inadequate information about HIV transmission, and the use of AZT therapy to decrease perinatal transmission (Flaskerud & Thompson, 1991; Sowell & Misener, 1996; Stewart, 1993). Other women may not believe that antiretroviral therapy will be beneficial to them or their babies. In fact, many women continue to perceive AZT as a harmful

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substance based on their own experiences with AZT and its side effects, and reports from other women with HIV (Balanon, Fordyce, & Stoneburner, 1990, National Institute of Allergy and Infectious Diseases, 1994; Sowell, Seals, et al., 1996). There is evidence that many women with HIV/AIDS are suspicious of the health care system and may not fully trust their health care provider, making them unwilling to accept AZT therapy (Austin & Dodge, 1992; Gentry, 1993; Misener & Sowell, 1998; Sowell, Seals, et al., 1996). This may be especially true of African American women in the Southern United States where memories of the Tuskegee syphilis experiment remain (Thomas & Quinn, 1991). Acknowledging the historical treatment of African Americans within the health care system, it is not surprising that Orloff and colleagues (1996) reported that African American women have the lowest rates of antiretroviral use during pregnancy.

The literature in health psychology and pharmacology documents several factors that influence decisions to take medications or to adhere to a treatment regimen. These factors include emotional acceptance of the need for and/or benefit of treatment, a belief that the prescribed therapy will be effective in treating the condition, financial resources to purchase the medication, social support, communication with health care providers, and the patient-provider relationship (Burke & Dunbar-Jacobs, 1995; Ickovics & Meisler, 1997; Rheiner, 1995). Misener and Sowell (1998), in exploring factors that influenced HIV-infected women's decisions to take antiretrovirals, found similar results. In that focus group study, HIV-infected women identified health professionals, beliefs about antiretrovirals, side effects, and attitudes of peers and family as important factors influencing their decisions to accept and adhere to AZT therapy (Misener & Sowell, 1998).

It may be particularly noteworthy that health care providers' approach to therapy, as well as the relationship between the patient and provider, has been identified as an important determinant in decisions to take medications (Erlen & Mellors, 1999; Lewis, Lasack, Lambert, & Connors, 1997). Living with a chronic illness results in a control shift as patients perceive limited personal control over their health. In addition, recurring medical treatment augments beliefs in influential or powerful others, namely, the health care professional (Nagy &

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Wolfe, 1983). One view is that surrendering control to powerful others is adaptive in situations where other persons may influence the situation (Affleck, Tennen, Pfeiffer, & Fifield, 1987).

There remains limited empirical data regarding the way in which HIV-infected women's evaluation of the patient-provider relationship and provider's attitude toward AZT therapy during pregnancy influence women's beliefs about the effectiveness of AZT therapy and their intent to adhere to a prescribed AZT regime if they become pregnant. Such data are needed if health care providers are to develop HIV treatment and counseling strategies that are successful in assisting HIV-infected women in making informed choices about pregnancy and the use of AZT therapy.

METHOD

This descriptive study used a cross-sectional sample of HIV-infected women who reside in Georgia and South Carolina and were at risk for becoming pregnant (i.e., able to become pregnant and sexually active). Potential participants were recruited from two HIV/AIDS service organizations cooperating in the study. Data were collected over a 4-month period using face-to-face interviews conducted by research assistants. All of the research assistants were extensively trained in data collection using an interview format. This study extends previous qualitative research exploring decision making related to becoming pregnant and use of AZT therapy among HIV-infected women (Sowell & Misener, 1996).

DATA COLLECTION TOOLS

To ensure cultural appropriateness and relevance of the study questionnaire, questions and scales used to collect data were developed with input from the population of interest (i.e., HIV-infected women in the South). In prior focus group work with HIV-infected women in Georgia and South Carolina by the lead researcher (Sowell, Cohen, Demi, & Moneyham, 1992), women indicated a preference for direct questions or short scales. To respect the women's perspectives, as well as keep the study questionnaire short to minimize participant burden, single item or short scales were used where possible.

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Demographic data. Demographic data were collected using a questionnaire that included age, family, household composition, education, employment, household income, and types of governmental services received (i.e., social security and food stamps). Women were asked specifically about the number of children they have and how many of these children were born since they became HIV infected. Women reported the HIV status of their children and whether they had a child who had died from HIV/AIDS. In addition, women were asked to report who served as their primary health care provider (i.e., doctor, nurse, or other).

Relationship With PHP Scale. Women's evaluation of their relationship with their primary health care provider was measured with a 12-item scale developed by Sowell, Cohen, et al. (1992) in a 3-year longitudinal study of the effect of HIV/AIDS on women and their families. The scale items were developed during eight focus groups with HIV-infected women and later tested using a sample of 264 women with HIV/AIDS. In that sample, the instrument demonstrated a Cronbach alpha reliability coefficient of .88. To complete the scale, women were asked to respond to questions related to their relationship with their PHP using a four-point Likert-type response scale ranging from *strongly disagree* to *strongly agree*. The scale included items such as: "My primary health care provider always tells me the truth," "I can talk to my primary health care provider about anything that concerns me," and "I worry about my primary health care provider keeping information about me confidential." Items were summed after reverse scoring negatively worded items for an overall relationship score ranging from 12 to 48.

AZT Effectiveness Scale. How effective women believed AZT therapy was in preventing the transmission of HIV from mother to baby during pregnancy was measured using a researcher-developed three-item scale. Women were instructed to respond to three statements about the effectiveness of AZT in decreasing perinatal transmission of HIV (i.e., "AZT is very effective in preventing transmission of HIV from mother to babies") using four-point Likert-type response scale ranging from *strongly disagree* to *strongly agree*.

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Health professional importance in AZT decision making. How important health care professionals/PHPs were in women's decisions to take or not take AZT was determined using one item. This item asked women to report how important health care professionals would be in their decision to take or not take AZT. This item was answered using a four-point response format (*not at all important, somewhat important, important,* and *very important*).

Evaluation of PHP attitude toward AZT. Women's perceptions of how positive their PHP was toward AZT therapy during pregnancy were assessed with a one-item, five-point scale. Women were asked to rate how they believed their PHP would feel about their taking AZT during pregnancy on a five-point scale (with 5 being *very positive or definitely wanting you to take AZT* and 1 being *very negative or not wanting you to take AZT*).

Intent. Women's intent to take AZT if becoming pregnant and intent to give AZT to their newborn for a recommended period after birth were measured using two questions. The first question asked women to rate on a five-point scale (with 1 being *would not take* and 5 being *would take*) how likely are you to take AZT if you get pregnant? The second question asked women to rate on a five-point scale (with 1 being *would not give* and 5 being *would give*) how likely are you to give your newborn baby AZT for 6 weeks after birth?

PROCEDURE

Research assistants were identified using the input from personnel of the cooperating AIDS service agencies. All research assistants were female and had experience working with women with HIV infection. None of the research assistants were providing direct services to the women they interviewed. The research assistants were trained as to the format and procedures to be used in the study. Selection criteria for potential participants were being of reproductive age (18 to 45 years), African American, verified HIV-seropositive status as documented by HIV testing in their chart, at risk for pregnancy (i.e., had not been sterilized or have a permanent contraceptive

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device), sexually active by self-report, able to speak and understand English, and no evidence of dementia. All women who met the criteria at the cooperating sites were asked to participate. Women who agreed to participate were interviewed at the cooperating agencies, in their homes, or at other mutually agreed on sites. The actual site for the interview was determined by the women in conjunction with the research assistant and was intended to provide a comfortable setting in which the women could respond to study questions. Before any questions were asked, the purpose of the study was emphasized to each woman and informed consent was obtained. All questions were read to the women, and their answers were recorded by the research assistant. Women were paid a $30 honorarium for their contribution to the study.

SAMPLE

The sample consisted of 59 African American women who had been diagnosed as HIV infected. Participants in the study represented women ranging from those newly diagnosed in the past 3 months to women who had lived with HIV for 5 or more years. The majority of the women (83%) received health care through one of five publicly funded clinics. Primary providers in three of the clinics were Caucasian males, in one of the clinics the provider was an African American female, and in the fifth clinic, the providers were of diverse gender and ethnicity. The remaining women received primary health care through a number of private providers. The women reported their place of residence as urban (65%), suburban (17.5%), and rural (17.5%). Women ranged in age from 19 to 45 years (M = 32.5 years, *SD* = 6.25). More than one half of the women were single (58.6%), and almost two thirds (63.2%) of the women had a high school education or higher. Most of the women (76.7%) reported household incomes of less than $10,000 annually. Most of the women (81%) reported having at least one child (range = 1 to 5). Almost one half (44.9%) of the women reported having had a baby since being diagnosed as HIV infected. Of those women who had a baby after becoming HIV infected, only 3 (6.7%) reported having an infected baby. Three women (6.7%) reported that they did not know their baby's status.

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FINDINGS

Fifty-six women responded to the question asking who provided their primary health care. Of those who responded, 50 (89.3%) reported their PHP to be a physician and 6 (10.7%) reported that a nurse provided their primary care. Interestingly, women who identified nurse practitioners as their PHP (M = 34.33, *SD* = 4.55) did not score significantly different on the Relationship With PHP Scale than women whose PHP was a physician (M = 36.34, *SD* = 4.67). The number of women identifying a nurse as their PHP was very small making further investigation necessary. Women reported that they had a relatively positive relationship with their PHP. Women's scores on the Relationship With PHP Scale ranged from 25 to 44 with a mean score of 35.9 (*SD* = 4.79). Data analysis showed a Cronbach's alpha reliability coefficient of .74 for the scale.

A majority of women evaluated the effectiveness of AZT in the prevention of perinatal transmission of HIV as being high. Although individual scores on the Effectiveness of AZT Scale represented the entire range of possible scores (3 to 12), the overall group mean score for this scale was 8.3 (*SD* = 2.44). Cronbach's alpha coefficient for internal consistency for the scale was calculated as .65. This value was judged as acceptable due to the sample size and the small number of items comprising the scale.

Pearson's *r* was used to examine the relationship between women's relationship with their PHP and how important health care professionals were in making the decision to accept AZT therapy, women's beliefs about the effectiveness of AZT in decreasing perinatal transmission of HIV, their intent to take AZT if they became pregnant, and intent to give AZT to a newborn. Data analysis revealed a significant association between woman-provider relationship and the level of importance played by health care professionals in the decision to take AZT ($r = .37$, $p = .004$). The more positive the relationship between the woman and the PHP was, the more important the PHP was reported to be in making decisions concerning AZT therapy (Figure 1).

Also, Pearson's *r* was used to examine the relationship of how positively women perceived their PHP viewed AZT's effectiveness in decreasing perinatal transmission and their own

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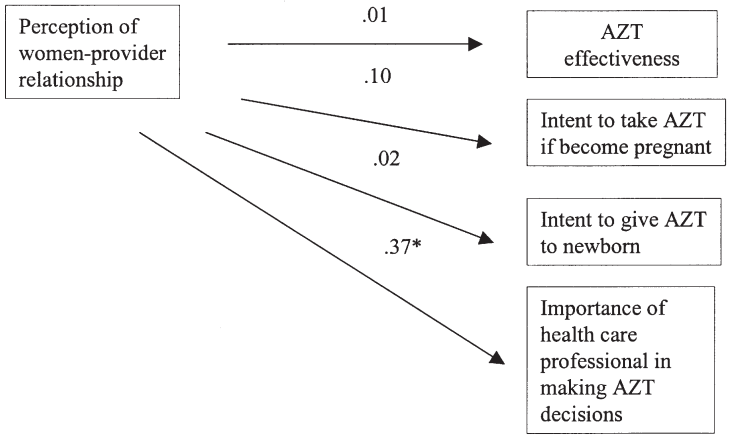

Figure 1. **Correlation coefficients between perceptions of women-provider relationship and women's evaluation of AZT effectiveness, how important health care providers are in making decisions to take AZT, intent to take AZT if becoming pregnant, and intent to give AZT to a newborn.**

evaluation of AZT effectiveness, their intent to take AZT if they became pregnant, and intent to give AZT to a newborn. As shown in Figure 2, a significant positive relationship was found between women's perception of how positively her PHP viewed AZT during pregnancy and their own evaluation of AZT's effectiveness ($r = .37$, $p = .01$), their intent to take AZT if becoming pregnant ($r = .59$, $p = .001$), and intent to give AZT to their newborns ($r = .48$, $p = .001$).

CLINICAL IMPLICATIONS

This study represents an initial examination of how HIV-infected women's relationship with their primary health care provider and their perception of the care provider's attitude toward AZT therapy during pregnancy relate to women's AZT attitudes and intentions. Whereas it is acknowledged that women's intentions related to AZT therapy cannot be equated with actual behaviors, intentions represent a necessary first

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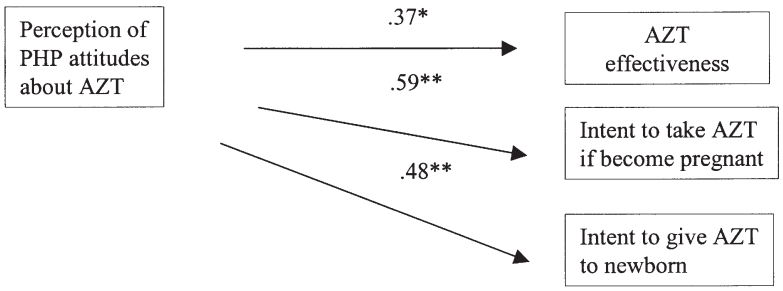

Figure 2. **Correlation coefficients between women's perception of how positively primary health care provider (PHP) views AZT therapy during pregnancy and women's evaluation of AZT effectiveness, intent to take AZT if becoming pregnant, and intent to give AZT to a newborn.**

step in taking an action. Although further research is needed that includes larger and more diverse samples, as well as measuring actual behavior, this study provides important insights into the correlation of two aspects of the patient-provider relationship with AZT beliefs and intention in a group of HIV-infected African American women.

Previous research has provided conflicting findings related to how positively persons with HIV/AIDS view health care professionals. Although some studies showed that persons with HIV/AIDS have had negative health seeking experiences (Bing & Soto, 1991; Siegel & Krauss, 1991; Sowell, Seals, et al., 1996), researchers exploring factors related to drug adherence reported that many participants identify their relationship with their provider as an important influence in their ability to follow complex treatment regimes (DiMatteo et al., 1993; Powell-Cope, 1994). Whereas women in the current study viewed their relationship with their PHP as more positive than negative, the results suggest that women were not totally satisfied with the patient-provider relationship or did not fully trust their PHP.

One possible explanation for this finding may lie in the historical treatment of poor and/or minority within the health care system (Bing & Soto, 1991; Mitchell et al., 1992). All the

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women in this study were African American, potentially adding an underlying sense of mistrust based on previous experiences of discrimination encountered within society in their daily lives (Moneyham et al., 1996; Timmons & Sowell, 1999). In previous research with a sample of primarily poor minority women in the South, women described concerns within the health care system about confidentiality, being given few options, and not being able to access services for which they were eligible (Seals, Sowell, et al., 1995; Sowell, Seals, et al., 1996). Women with HIV infection, similar to other individuals seeking health care, need to be educated about their illnesses and potential therapies and allowed to participate in choosing and managing treatment options (Taylor, 1991; Ungvarski, 1997; Williams, 1997).

It might be expected that women who had a positive relationship with their PHP would have more positive attitudes and intentions toward AZT therapy than women who had a negative relationship with their PHP. However, the findings show that the relationship between women and their PHP was not significantly related to women's evaluation of AZT effectiveness, their intent to take AZT if becoming pregnant, or intent to give AZT to a newborn. This finding may have partially resulted from the relatively small sample size and the fact that most women had a somewhat positive relationship with their PHP. A third consideration is that it may not be the actual patient-provider relationship that influences women's beliefs and intentions related to AZT therapy but, rather, the communication and perceptions about such therapy that women get within the relationship. Women may have a very positive relationship with their PHP but that does not necessarily mean that individual providers adequately communicated information about AZT therapy or its benefits in decreasing perinatal transmission of HIV. However, the results did show that how positively women evaluated their relationship with the PHP was significantly related to how important the health care providers would be in making AZT-related decisions. The patient-provider relationship provides the context in which communication about AZT therapy takes place.

An examination of women's evaluation of the effectiveness of AZT as a way to decrease perinatal transmission of HIV showed that most women view AZT as having value in preventing

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transmission to a baby. However, a group of women indicated they did not believe AZT was effective in preventing perinatal transmission. This finding underscores the need for health care professionals to fully assess women's attitudes toward antiretroviral therapy and realize that even if the women feel compelled to accept therapy, they may not adhere (Sowell, Seals, et al., 1996).

One of the most important findings in this study supports the importance of perceptions and communications within the patient-provider relationship. Although women's evaluations of their relationships with their PHP did not relate significantly to their AZT beliefs and intentions, women's perceptions of how positively their PHPs view the use of AZT therapy during pregnancy did. Data analysis revealed a significant positive relationship between how favorably the PHP views AZT as a way of decreasing perinatal pregnancy and women's evaluation of AZT effectiveness in decreasing perinatal transmission, women's intent to take AZT if becoming pregnant, and intent to give AZT to their newborns. This finding underscores the benefit of clear and honest communications between HIV-infected women and their PHP. Furthermore, this finding supports the value of health care professionals going beyond the presentation of facts and figures in their education and/or counseling of HIV-infected women. In educating women about AZT therapy during pregnancy, it may be equally as important for health care professionals to communicate a positive personal evaluation of such therapy as it is to present statistical data from clinical trials such as ACTG 076.

Although intentions to take AZT are influenced by many relationships, including family and peers, the results of this study support the importance of the patient-provider relationship in treatment-related decision making. The fact that women's AZT beliefs and intentions are significantly related to their perception of how favorably their PHP views such therapy provides important data that can be readily integrated into clinical practice. It is important for PHPs to critically examine their approach to treating poor women with HIV to ensure that interactions are respectful, culturally appropriate, and take into account the importance of women's perceptions of provider attitudes in making treatment decisions (Charonko, 1992; Crespo-Fierro, 1997).

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