
CLOSE RELATIONSHIPS AS SOURCES OF STRENGTH OR OBSTACLES FOR MOTHERS COPING WITH HIV

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The current study explores the impact of HIV disease on the interpersonal relationships and social support experiences of mothers living with HIV. Analysis of interviews with 25 mothers with HIV focused on their perceptions of the impact of HIV on close relationships with significant others, including family of origin, children, friends, intimate partners, and parents. The results revealed the following major relationship challenges that mothers had to cope with after the discovery of their HIV-positive status: weighing reasons for and against disclosure of their HIV

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status, whether HIV disclosure brings relationship partners closer together, finding future caregivers for young children if one's health declines, and coordinating safer-sex practices with sexual partners, especially with the many males who are reluctant to use condoms. The study suggests the importance of understanding both the positive and negative aspects of social interactions in coping with HIV and the struggles that mothers have with the consequences of the HIV diagnosis for both themselves and their significant others.

There are considerable stressors associated with the discovery of a positive diagnosis of HIV. In addition to the physical aspects of living with HIV disease, there are numerous psychological and social stressors that HIV-infected persons may confront. These include disruptions in close relationships, loss of work, discrimination, and stigma (Chidwick & Borrill, 1996; Leary & Schreindorfer, 1998; Semple et al., 1993; Stevens & Tighe Doerr, 1997). Studies of HIV indicate that the psychological and social stressors connected with HIV may affect how well one adjusts to the disease and perhaps influence disease progression and mortality (Cole, Kemeny, Taylor, Visscher, & Fahey, 1996; Leserman et al., 2000; Moore et al., 1998; Segerstrom, Taylor, Kemeny, Reed, & Visscher, 1996).

Much of the research in the United States on psychological and social stressors in living with HIV has been conducted among gay men with HIV, partly because this population was the earliest and largest single group living with HIV in this country (Centers for Disease Control and Prevention [CDC], 1999; Shilts, 1987). There has, however, been an upsurge of research recently on psychological and social issues among women with HIV, including trauma at the discovery of the diagnosis, depression, self-disclosure of HIV, condom use, risk of physical violence, and parenting (e.g., Demi, Moneyham, Sowell, & Cohen, 1997; Kotchick et al., 1997; Kwiatkowski & Booth, 1998; Miles, Burchinal, Holditch-Davis, & Wasilewski, 1997; Simoni et al., 1995; Simoni, Walters, & Nero, 2000; Stevens & Tighe Doerr, 1997; Vlahov et al., 1998). These studies have identified some of the differences in the ways that women experience the disease, both physically and psychologically. However, research is limited on how HIV disease affects women's close relationships.

In this study, we examined the ongoing relationship issues faced by mothers with HIV. Our research was conducted in the South, the region with the greatest increase in AIDS incidence for women in the United States (Wortley & Fleming, 1997). The goal of the study was to increase our understanding of the processes associated with interpersonal coping (including women's decision making about HIV disclosure, social support seeking, and the support they are given in their different relationships) and how coping with HIV

influences personal and relationship well-being. We focused on HIV and women's relationships with a variety of social partners, including family members, children, lovers, and friends. Many relationship issues (e.g., HIV self-disclosure) are likely to cut across a variety of relationships, but some issues are unique to certain relationships (e.g., condom usage).

Psychological and Social Issues Faced by Adult Women Living With HIV

Issues that are likely to differentiate the lives of women coping with HIV or AIDS from those of men include care-giving status, ethnicity, economics, sexuality, and community. First, although most women and men are parents, women are generally the primary caretakers of children; in single-parent or divorced families, women are often the sole caretaker; and among HIV-positive individuals in the United States who are parents, women (76%) are more likely than men (34%) to be living with their children (Schuster et al., 2000). In the sample of 25 mothers with HIV interviewed in the present study, in only one case was the biological father involved with his child on a daily basis. Being a caregiver while ill with a chronic and life-threatening disease poses serious challenges for women with HIV or AIDS.

Second, in the United States, women with HIV or AIDS are more likely than men to be of minority status (CDC, 1999). Internal and external barriers to health care and/or social support are influenced by sociocultural factors. For instance, African Americans or Latinas may mistrust information given to them about HIV and AIDS (Gamble, 1997; Jones, 1993; Owens, 1995). Furthermore, the communities of color most affected by HIV and AIDS are already suffering from multiple stressors that make it difficult to address the needs of community members with a chronic, life-threatening, and transmittable illness (Gasch & Fullilove, 1994).

Third, being female and Black or Latina each increases the likelihood of being poor. Economic difficulties and living in poverty are problems for many HIV and AIDS populations, but especially so for women, minority women, and women who must provide economically for their children (Zierler et al., 2000).

Fourth, most women with HIV or AIDS are heterosexual (92% in our study). The affected population of men who have sex with men has faced the stigma of this sexual orientation in combination with the illness (Cole et al., 1996; Collins, 1998). Although the stigma of sexual orientation is not present

for most infected women, they are likely to be viewed negatively in regard to lifestyle and sexual behavior. Furthermore, lack of awareness of HIV and AIDS in the heterosexual community may make pursuing intimate relationships more difficult for women with HIV than for gay or bisexual men. Finally, whereas the gay communities have tended to invest in education, prevention, and support of persons with HIV and/or AIDS, heterosexual women with HIV or AIDS may find themselves without these sources of community support (Collins, 1998; Weston, 1991).

Finally, although the majority of women with HIV or AIDS contract it through sexual relations, as do men, proportionally more women than men report transmission from intravenous (IV) drug use and/or sexual relations with a partner who is an IV drug user. As Jenkins and Coon (1996) note, "When HIV risk enters women's lives, it enters lives that contain other stressors" (p. 39). Given the significance of the issues facing women living with HIV or AIDS, scholars have lamented the relative paucity of research about these women (Ickovics, Thayaparan, & Ethier, 2001; Stevens & Tighe Doerr, 1997). Recently, researchers are exploring the lives of women with HIV.

Relevant Research on Women With HIV

Semple et al. (1993) identified stressors in a sample of 31 HIV-positive, mostly White, heterosexual women with no reported history of intravenous drug use. The researchers identified self-disclosure of HIV status to children, concern about having infected children, caring for an infected child, and making alternative arrangements for caring for children as important stressors in the lives of the women who had children. Self-disclosure in general was reported to be stressful. Overall, the most stressful events for these women were learning their diagnosis and chronic financial strain. The authors acknowledged, however, that this sample of primarily White, heterosexually infected women was not representative of the overall population of women with HIV.

In a study that explored the life concerns of eight women living with HIV, stigma was the most frequently cited concern (Hackl, Somlai, Kelly, & Kalichman, 1997). Women also expressed fear of rejection and worry that their family was threatened by potential shame. Other major concerns were caregiving to children, obtaining social support, death and dying, and need for information about the illness. The primary coping strategies used by these women were denial and concealment; they also used keeping away from others and crying. However, these were women who had known of their

diagnosis on average for less than 1 year and, therefore, probably represent the early stages of coping with HIV seropositivity.

In a sample of 264 women with HIV from urban and rural treatment sites, responses to open-ended questions yielded eight categories of coping: seeking/using support, spirituality, avoidance/denial, focusing on the here and now, managing the illness/promoting health, positive thinking, focusing on others, and information seeking (Demi et al., 1997). These responses were judged to be similar to those used by men with HIV, except for a greater emphasis on spirituality and focusing on others. In a follow-up study, Moneyham et al. (1998) found that active coping (including seeking support, spirituality, and managing the illness) was related to lower levels of emotional distress. Active coping also predicted a reduction in physical symptoms 3 months later.

Deciding whether or not to disclose about the HIV diagnosis is a major concern for women. On the basis of interviews with HIV-positive women, Kimberly, Serovich, and Greene (1995) described six steps women experience as they decide to disclose this information: (a) adjusting to the diagnosis, (b) evaluating personal disclosure skills, (c) taking inventory of whom to tell, (d) evaluating potential recipients' circumstances, (e) anticipating reactions of the recipient, and (f) having a motivation for disclosure.

In a study of 82 women living in a rural area (68% African American, 32% Caucasian), health care providers were the most frequent target of disclosure; 90% reported having disclosed to all health care providers and 6% to some (Sowell et al., 1997). These women disclosed at lower rates to sexual partners; 69% reported having disclosed to all of their sexual partners. They also reported having disclosed to some or all of the following: parents (78%), close friends (59%), children (51%), and other relatives (50%). A study by Simoni et al. (1995) of 65 ethnically diverse HIV-infected women at an outpatient clinic in Los Angeles found relatively low rates of self-disclosure to extended family (22%–28%), moderate rates to immediate family (31%–59%), and high rates to friends and lovers (78%–87%).

Relationships with sexual partners are inevitably affected by a diagnosis of HIV. The decision to disclose one's status to a current sexual partner or to future sexual partners is a stressful one. Women may fear abuse or rejection. The initiation of safer-sex practices is an issue. In the baseline data collected for the HIV Epidemiology Research study, conducted at four sites, women with HIV were more likely to be sexually abstinent in the past 6 months (27%) than uninfected women (15%) (Smith et al., 1996). Of women who had sex with male partners, only 53% of HIV-infected women reported that their partners always used condoms. In a study of safer sex among women with HIV, Simoni,

Walters, and Nero (2000) found, similarly, that 46% of these women had engaged in vaginal sex without a condom in the past 90 days. Surprisingly, women with a steady partner were far more likely to report unsafe sex (61%) than respondents without a steady partner (16%). However, among women with steady partners, women in longer and more supportive relationships reported more consistent condom use. Partners' HIV status did not predict condom use, but among women with HIV-positive partners, length of relationship predicted condom use, and among women with HIV-negative partners, time since HIV diagnosis predicted condom use.

Researchers have also explored the impact on children of having a mother with HIV. The Family Health Project has studied African American mothers and their noninfected children in a low-income, inner-city environment. Forehand et al. (1998) found that, in comparison with children of mothers of comparable sociodemographic backgrounds, children (6–11 years of age) whose mothers are HIV positive have more difficulties with externalizing problems, internalizing problems, cognitive competence, and prosocial competence. In a subsequent study (Klein et al., 2000), the mothers with HIV were found to report lower levels of social support from neighbors and friends and lower levels of emotional support from their children. They also reported higher levels of psychological distress. However, support from other adults alleviated stress for mothers, and support from the mother benefited her child (Klein et al., 2000).

Looking at the impact of a mother's disclosure of HIV status to her child, Armistead, Tannenbaum, Forehand, Morse, and Morse (2001) found that 30% of the mothers had disclosed to the identified child (6–11 years of age). About half of the mothers perceived a positive response from the child, and about 40% perceived a negative response (anger, rejection, fear, disappointment). Although neither stage of illness nor time since diagnosis was related to disclosure, mothers' self-report of symptoms was related to disclosure of HIV status. Older children and female children were more likely in this sample to be targets of mothers' disclosure. Although the mother's physical symptoms predicted the child's levels of anxiety/depression and aggression on the Child Behavior Checklist, disclosure of HIV status to the child did not predict the child's internalizing or externalizing behavior.

Rationale for the Present Research

These studies indicate that mothers coping with an HIV diagnosis face several different challenges: having a life-threatening illness, having an illness

that is associated with social stigma, not infecting others with this deadly disease, and parenting a child within the context of these challenges. What remains unknown is the impact of HIV on women's multiple personal relationships and their response to changes in these relationships. We systematically explored the impact on close relationships of the HIV diagnosis by examining women's narratives.

Method

Research Participants

Twenty-five mothers, recruited from HIV/AIDS service organizations in Norfolk, Newport News, and Richmond, Virginia, in 1997–1998, participated in this study. A flyer was distributed by case managers to female clients at these agencies requesting participants for an interview study about mothers' experiences living with HIV. The women were each paid \$10 for participating. Participants ranged in age from 18 to 54 years, with an average age of 35 ($SD = 9.13$). Sixteen (64%) were African American, and nine (36%) were European American. Most were not currently working (72%) and reported low incomes ($M = \$10,071$, $SD = \$5,196$, range = \$3,000–\$20,000). Seventeen participants (64%) reported HIV transmission from a heterosexual partner, and eight (32%) reported histories of IV drug use (but were often uncertain whether shared needles or sexual relations with infected men had actually been the source of transmission). One woman was uncertain how she acquired the virus, although she had been in a relationship with a man from whom she had caught various other sexually transmitted diseases. The ratio of twice as many cases from heterosexual contact as from drug use is similar to that reported by the CDC (1999). Unlike the CDC samples, however, all but one of these women believed that they could identify the source of their HIV infection. There was a trend toward a relationship between ethnicity and mode of transmission. Eight of the 16 (50%) African American women and one of the 9 (11%) White women reported transmission by IV drug use (Fisher's exact probability = .09).

The women who participated in the study had an average of 2.28 ($SD = 1.17$) children, ranging in age from 1 year to 31 years. They had known their diagnosis for 5 years on average, ranging from 1 year to 12 years. Their average self-reported CD4 cell count was 461 ($SD = 236$, range = 13–1,000).

Procedure

The women first completed a brief demographic questionnaire, providing information about their age, ethnic background, how they acquired the HIV infection (sexual transmission, blood transfusion, or IV drug use), what year and month they had been diagnosed as having the HIV infection, and their most recent CD4 cell count (a CD4 cell count below 200 is an indicator of AIDS; Bartlett & Gallant, 2001). Interviews were conducted by the second author. The interview began by asking the women to think about and recall the impact of HIV on their close relationships, including family, friends, intimate partners, and their children. The women were asked to recall when and how they had learned about their HIV diagnosis; with whom, from the time of the diagnosis until now, they had talked about their HIV diagnosis; and how having HIV had affected their close relationships. Interviews generally lasted from 60 to 90 minutes.

The following steps were used to develop inductively a coding scheme to describe the data collected from the interviews. First, all interviews were initially tape recorded and transcribed. Second, three of the researchers independently reviewed eight randomly selected transcripts to devise an initial coding scheme of relationship issues reported by the women. Third, these researchers met together to discuss the coding scheme that included categories capturing participants' own reactions to discovery of the HIV diagnosis, reasons for and against self-disclosure of HIV status, and relationship changes that occurred with significant others. Fourth, the coding scheme was applied to all transcripts by two trained coders who independently decided whether various types of subjective experiences and social interactions were reported by the research participants. There was adequate agreement among the coders in using the various coding categories constructed for the study (percentages of agreement in coders' categorizations varied from 80% to 100%). When there was a disagreement between the two coders in the categorization of particular content, one of the authors served as the tiebreaker. Fifth, we used the relative frequency of experiences reported by the participants as the data for the study, allowing us to identify not only whether women reported certain relationship experiences but also how many of the women in the sample reported these experiences. Finally, excerpts from the interviews are used to illustrate the types of HIV-related relationship and other concerns reported by the women.

Results

Avenues of discovery of HIV seropositivity were diverse for these women. The two most frequent reasons for testing (each 20%) were current illness (e.g., cold, flu, or persistent diarrhea) and pregnancy, childbirth, or postnatal exam. Three women (12%) sought testing after learning that their sexual partners were positive; another woman was contacted for testing by a local health department (having been identified by one of her previous sexual partners who tested positive); and one was told by a former sexual contact that his girlfriend was positive, which prompted her to get tested. Other reasons for testing included blood donation, regular testing, and being in drug rehabilitation or a mental hospital.

As in Stevens and Tighe Doerr's (1997) research, most of these women responded to their HIV diagnosis as a calamity. Sixty percent reported that, when they first learned of their diagnosis, they thought they were "going to die," and/or they were "shocked," "devastated," or "totally surprised." Three women (12%) reported that they considered or attempted suicide.

The following results are organized according to the relationship-related themes coded in the transcripts, specifically: HIV decision making; perceptions of the concerns and behavior of the women's children; issues regarding responses of family, friends, and partners to the women's HIV seropositivity; and issues regarding safer sex and condom use.

HIV Disclosure

Women varied widely in their approaches to sharing information with others about their HIV seropositivity. For instance, Kim (all names are fictitious) was tested after her husband told her he was HIV positive. She had her parents, brother, and grandmother with her when a health department representative was expected to call with the test results. Kim recalled, "They [the relatives] took off from work, 'cause we knew that was the day we'd get the results." In contrast, Liz, even though she lived with her father, had not yet told any family member and, after 1 year of knowing she was HIV positive, had disclosed this information only to a therapist, two close friends, and a coworker. Other women, who were reluctant to disclose when they first knew their diagnosis, became more open with time. Della reported having protected sex with a man but not telling him her diagnosis until afterward. After their relationship ended, she discovered he was telling mutual friends about her HIV status. Della said:

I made up my mind that I was gonna tell it myself. And I told him, "You don't have to tell nobody, 'cause I'm gonna tell it myself." And that is the first thing that started me being so open and honest about the diagnosis.

Linda also became more comfortable disclosing her HIV status, but she credited therapy with her growing sense of responsibility and comfort in telling others.

Although many women became more open over time, most reported struggling with whom to tell, when to tell, and how to tell this information. Most had experienced stigmatization, including having a sister Clorox the toilet after the woman with HIV used it, having a relative refuse to eat off the same plate, and being asked by school personnel not to volunteer in the classroom.

Reasons for Disclosure

Fifteen women (60%) cited the need for *emotional support* as a reason for telling others. For instance, Paula said, "At first I didn't want to discuss it, but I just felt the need that I had to tell somebody, because maybe that would make me feel better, to maybe hear somebody just give me some comforting words."

Eight (32%) wanted support in the form of *advice and help*. Paula's husband, who was also positive, did not want anyone to know. Paula recalled, "He didn't really have too much to say about me being HIV positive, because I told him that this [telling health professionals] is what I was going to do, because I needed some help. I needed to start taking medicine."

Twenty-four women (96%) had a *prosocial motive*; they wanted to *educate* others or *protect* them in some way. Thirteen (52%) mentioned the need to tell another person for the other's protection. Maggie said, "The very first person [I told] was the person I was somewhat involved with. I called him up." Sheila explained that she "went back to the person and . . . talked to the person about it, and told that person to go get tested for it." Eleven women (44%) wanted to educate others. As Kim said, "I always tell people. I have spoken before groups before. I'll tell them to ask me anything they want, and I answer everything." Della also described her efforts to educate others:

I think the more people will come out of the closet with their status, if I may use that term, and let the world know, "Hey, I am a person that has been diagnosed with this virus, but I am still a human being. And I'm living. How do you want somebody to treat you?" And they will say, "Well, like a human being?" I say, "Well, I appreciate it if you treat me the same way, because I'm a human being only living with the disease."

Seven women (28%) felt that others had a *right to know*. Paula said, "I told him before we went to bed, you know, had a sexual relationship. I told him in advance to let him know what was going on."

The final overarching reason for disclosure was *catharsis*. Eight women (32%) wanted *emotional release*. As Sarah explained, "I just wanted to share it. It's an awful burden to carry by yourself, you know. It's good to have somebody else to share it with, and I just wanted to tell some friends." This was particularly the case when others had *similar problems or backgrounds*, as reported by five women (20%). Maggie, for instance, described telling her friend at work:

I always knew I could talk to her, but I just had to wait for the right moment. Her husband has an uncle that has AIDS and she shared with me one day about him being sick. . . I told her everything.

Monica recounted:

I do have one good friend. I used to date the same guy she used to date. She was talking to me one day. I was talking about not letting guys use her and she was crying and she told me she had herpes, and I was like, "What I have, I wish I had herpes." And she said, "What are you talking about?" And I told her about this and she was crying and said, "Oh my God, I thought I had a problem."

Reasons for Nondisclosure

The most frequent reason given for not disclosing, expressed by 17 women (68%), was *fear of rejection or stigma*. Liz explained:

This sounds sort of sad, but I think she [her grandmother] would almost think about cutting me out of her will or something like that if she knew. You know, because the first thing that people ask me is, "How did you get it?" and that's just, that's very personal.

Sarah lamented, "I felt that they [her family] were going to just kick me aside, just run away from me, not even want to be in the same room." Explaining why she did not tell friends about her illness, Tina said, "Rejection. I just don't want to be alone."

Twelve women (48%) were concerned about their *privacy* and controlling gossip. Linda said, "I always had that fear, and I still do have that fear to this day that the people who do know, who are they telling?" Sheila explained, "I mostly try to stay away from people that I know are going to talk, that are going to run their mouths."

Another reason for avoiding disclosure, expressed by seven women (28%), was a *desire to protect others*. Carolyn said, "I don't want to tell him [her father] because he's recovering from alcohol and I don't want to give him a reason to drink." Charlene explained that she didn't disclose to her mother "because my brother died from it. . . . My mother has been through a lot, and I just don't want her to go through a lot."

Eight women (32%) *felt unprepared* to tell others. As Tonya explained, "I was still in denial then. I didn't care if my family knew, close family, but I didn't want nobody else to know." Laura said, "I think first I had to deal with it myself, so I went through a time period of fear of telling anyone." Additionally, eight women felt that certain *relationships were too superficial* to warrant HIV disclosure. Liz said, "It's bothersome to have that secret, and yet at the same time, I don't really want to divulge that kind of information to someone who I don't really know."

Finally, seven women (28%) felt tainted or *ashamed* of the HIV diagnosis. Liz said, "He [her son's father] was the last person I told. It was a little bit to do with guilt, feeling like a failure." Others expressed this shame in terms of *family shame*. In four cases (16%), family members had asked the women to keep the information secret. Brenda reported, "My mom would rather me not tell my family. She just said, 'I would rather not for the family to know right now.' That's all she said."

Others' Enactment of Social Support After HIV Disclosure

Support seeking was a primary reason the women gave for disclosing their HIV seropositivity. Analysis of the main sources of social support revealed that family was the most supportive; however, specific sources of support varied to some extent by ethnicity. Five White women (55%) mentioned some member of their family as being supportive, as compared with 13 of the African American women (81%). African American women were especially likely to mention their mothers (50% of the sample) as their major source of support relative to White women (11%), who were more likely to mention sisters, fathers, or both parents. African American women spoke of having a bond with their mothers and having their mother as a best friend, whereas White women were more likely to mention parents in protective roles or as providing financial support. Although the numbers suggest differences between ethnic groups, Fisher's exact probability tests (used owing to small cell sizes) did not yield statistically significant results for these comparisons.

HIV-Linked Relationship Issues With Children

One mother had lost a child who was born HIV seropositive; six other women bore children when the women were HIV positive, and the children were negative or had converted to negative with time. Seventeen women (68%) had told their children about their HIV seropositivity. Four of the eight women (50%) who had not talked to their children about their diagnosis had children who were 3 years of age or younger. Two women had children in the 5–7-year range, whom they deemed to be too young to be told, although other women had told their children this young. One woman had children aged 10 and 12, whom she still regarded as too young, and one mother had children 14 and 19 but did not disclose this information, as she had little contact with them owing to a long history of drug abuse. She thought they might know about her diagnosis from their caregiver (her mother-in-law), but she herself had never talked with them about it.

Children's Responses

Mothers generally perceived their children who knew about their diagnosis as being accepting and loving (82%) and protective (59%). As Martha said:

At first [their response] was very protective. They [children] would want to keep me in bed, bring me tea or toast or whatever. They'd want to take care of me, to nurse me. I immediately put a stop to that. I don't want them being overly concerned.

Carla also described her children as protective:

They know the schedule [of medications]. They're like, "You know you have to take your pills, Ma." They get mad at me when I don't take them. . . . It makes me feel good that they're with me; they're in my corner.

Six mothers (35%) reported that their children reminded them of their medications.

Another impact on the children was of an emotional nature; mothers reported that their children were *fearful of the unknown* (41%) and of *separation and death* (59%). Laura said:

My kids were not used to seeing me lay down. They would get upset and say, "Mom, are you okay?" But I could see the fear in them that this might be it. My daughter had a conversation with me and she told me, "You don't understand, Mom. You're learning how to cope with this, but my brothers come to me every night and say, 'What happens if Mom dies?'"

Sheila recounted:

It's affecting them [her children] terrible because they just don't know how to deal with it. They're trying to deal with it, but I know in their hearts, they think about this every day. When they go to sleep, I think they think, "Well, Momma's going to sleep and I don't know if she's going to wake up." Or "How are we going to deal with this if anything happens to her?" They don't come out and talk about it, but I think they are thinking about it.

Six mothers (35%) also perceived their children as being *angry*. Martha said, "My son was very upset, and still is, that this guy did this to me, and he's mentioned that he wants to get him; when he grows up, to get him."

Four mothers (23.5%) reported that their children were in *denial*. Maggie described her son, with whom she has had no "real deep conversation" about the infection: "Probably it's something he's blocking. I think when he's ready, he'll come to me and initiate the conversation himself. At this moment, I don't press him." In contrast, however, seven mothers (41%) said their children wanted *more education about HIV/AIDS*.

Impact on Children's Social Relationships

Although no mothers reported that their children were concerned about others knowing about their mother's HIV diagnosis, some related painful experiences of others knowing this information. Three mothers (12%) of school-aged children advised their children not to tell others and to keep it to themselves. Vicky, a mother of a 9-year-old daughter, advised her not to tell anyone "because you don't know what kind of reaction you're going to get." However, while visiting friends, including another mother with HIV, Vicky's daughter told a child in this family's neighborhood that the families had met in a support group for people with HIV. The friend was "fit to be tied," and Vicky was "flabbergasted. We sat down so many times to talk about this and I can't believe she did that." The friend told her neighbors this information was false (even though it was not) because she did not want them to know she was HIV positive.

There were often negative consequences to being open about one's HIV status. Linda, who told her daughter when she was 13, described what happened:

She told a couple of her friends that year; and they were close friends; and I'd say within 6 months time she lost all three friends—the first friend because of the parents. The parents found out and told their child she was no longer allowed at my house. From that point on, her relationships have been kind of bumpy.

Peggy was not allowed to go into her daughter's school and help in the classroom after her daughter revealed her HIV-positive status. Two women reported that their children (a son and a daughter) got into fights at school about their mother's HIV status. Laura reported that her son told her, "Well, I don't like the fact that he said, 'Your mom has AIDS,' so I beat him up." Tonya lamented, "They used to write on the bathroom door at high school, 'Your mom's got AIDS and she's going to die,' and she [the daughter] used to get in fights so much about it." This mother learned from her older daughter's experiences that being open about her diagnosis may be harmful to her child. Later, when she was invited to be a featured guest on a local television show about HIV and AIDS, she asked her younger daughter about it and the daughter said, "Mommy, please don't do that to me."

Mothers as Role Models

Eleven mothers (65%), and nearly all of those with teenaged or preteen children, had talked explicitly about the importance of abstinence or safe sex with their children and had used themselves as examples of what their children should avoid. Carla described her conversation with her teenaged daughters:

I even talk about sex to both of my daughters and I tell them, "You want to have sex, make sure you have condoms. . . . Always carry one with you, you never know." They said, "I'm not ready for sex right now." I said, "Well, that's true, too, but you may be in a predicament, in a place where you say you're not ready, but you are ready. What if you're with a man and the man starts kissing on you and whatever and pop goes the weasel. So it's best to be prepared."

Maggie, the mother with a teenaged son, said, "I always stress to him, 'Whatever you do, please use condoms. I don't want what has happened to me to happen to you. Just listen to somebody you know.'" Della explained:

And I may say, "So, who're you dating now?" Or "The last girl you brought around, her dress was kind of short," and so and so. "Do you use condoms with her?" You know, I put condoms in his jacket pockets. I always ask him, "Are you using them?" He'll say, "Yeah." I don't sometimes believe it, because I know that men really don't like condoms.

Concerns for Children

Mothers' concerns for their children included *establishing future caregivers*. Fourteen mothers (74%) with children who were not adults or not already in the care of others had chosen a caregiver for their children; 86% of these

caregivers were family members. In only two cases did the mothers anticipate the children's fathers being the children's future caregivers.

Half of the mothers also reported feeling the *need to spoil or spend extra quality time* with their children. Peggy, whose daughter tested seropositive for 2 years before she converted to seronegative, described how her child "took a crayon and drew on the wall. It's not that big a deal. . . . She may not live to see 3, so I'm not gonna punish her for this." Carolyn said of her son:

I would tell him to sit down and he would tell me "No," and, you know, every time you tell your momma "no" you get your tail popped, but I don't bother with him. I'd be like, "Just come here and sit beside Mommy." And he comes and sits beside me and I love him and stuff.

HIV-Linked Relationship Issues With Intimate Partners

Relationships with husbands, boyfriends, and lovers are perhaps most affected by the HIV diagnosis. Ten women (40%) were married and 10 others (40%) were in dating relationships at the time of their diagnosis. In these 20 relationships, 11 of the men (55%) were also HIV positive; in four cases, the HIV-positive partner had died by the time of the interview. Of the 20 women who had heterosexual relationships at the time of the diagnosis, five (25%) reported feeling closer to their partner following the diagnosis (two of these women helped care for an HIV-positive partner who later died) and 12 (55%) reported experiencing conflict, blame, or the end of the relationship.

These 20 women demonstrate some of the varied patterns that heterosexual relationships can follow. Two married women discovered that their husbands were bisexual, and these relationships ended in divorce. In three cases, husbands who were HIV negative were unable to cope with their wife's status and left her (one left 5 days after she got out of the hospital with the illness that led to her diagnosis). One woman believed her partner was aware of his own HIV-positive status but had not revealed it to her, and she left him in anger. Two women stayed with their HIV-positive partners and cared for them until their deaths. Four other women (three with HIV-positive partners and one with an HIV-negative partner) cited other reasons for the end of their relationships. One woman described how she and her HIV-positive partner stayed together because they felt they had no other options; however, they blamed one another for their infections and eventually ended the relationship. Only four of these 20 relationships were still intact at the time of the interviews. Three of these women reported that their partners were HIV negative,

and the fourth was uncertain about her partner's HIV status. One of these partners had been steadfast in his support since learning of the woman's diagnosis; another began drinking more and had a strained relationship with the woman; a third told his female partner that no one else would want her (although she responded, "You wanted me. What makes you think somebody else is not going to want me?"); and the fourth seemed unaffected by knowing that his partner was HIV positive.

Starting New Relationships

Most of the women in the sample faced not only dealing with a relationship at the time of the diagnosis but also dealing with the issue of starting a new relationship. Of the 25 women interviewed, 15 had attempted new relationships; one of these was currently in a relationship with another woman. Of the 14 women starting a heterosexual relationship, two had formed relationships with men who were also HIV positive. Lisa explained how she decided that "I wanted to date men who had the disease, because then I didn't have to worry about telling them everything." Six of 12 women (50%) beginning relationships with men experienced rejection at least once after telling their partners of their HIV status. Laura related this story:

I met this guy that I really could have liked that had an interest in me. We were calling and talking, kind of dating. When I did tell him, I think it was about the fourth time that we talked . . . it was like, that's it. I never heard from him again. . . . He said, "You don't look like a person that has HIV." I'm like, "What does a person look like that has HIV? I am a person, I comb my hair, I wash my body, I eat." It was devastating. If I live another 9 years, it will be just by myself. I think I'll be taking my chances by myself [rather] than [risk] getting hurt.

Four of the five women who were not in relationships when they learned their diagnosis and three of the women whose relationships had ended chose *not* to pursue new relationships, one after having been rejected in her first effort at establishing a new relationship. Liz said, "I just feel like I have to be confident enough in my own dealings with this before I can expect anyone to help me deal with it."

Condom Use

Of the 11 women in relationships with HIV-positive partners at the time of their diagnosis, only one regularly used condoms with her partner. Most explained that they were unaware at the time that there was any danger in having unprotected intercourse if both partners were already infected.

In contrast, the two women who began new relationships with HIV-positive partners always used condoms. Peggy, whose HIV-positive ex-husband would not always use condoms, described how condom use in her new relationship “wasn’t an issue, because I had not already had unprotected sex with him. . . . Condoms right from the beginning were just a normal state of affairs.”

Of the 14 women who described having sexual relations with uninfected men, four said they had always used condoms. Only two of the women described histories of not telling their partners of their HIV status. In every other case, the women informed their partners of their HIV status, but their partners refused to use condoms. These men insisted that they would not be infected, or, in Sheila’s words, “they didn’t care if they caught it or not because they had gotten into a relationship with me and cared about me and loved me as I am. . . . They said, ‘If you die I will die with you.’”

Negotiating condom use, whether successful or not, was a source of stress for these women. Lisa, who insisted that her husband use condoms, explained, “His reaction was that . . . since he had never gotten that, it was a waste of time for him to put a condom on. . . . He said the condom didn’t make him feel right. So anytime we got ready to have sex, we always had a battle.” Linda, who always used condoms, said:

It was automatic that he used a condom. And then there were a couple of times that he didn’t want to use a condom, and you know things would get heated. We would have to actually stop and say, “Wait a minute. What are you doing?”

Della, another regular condom user, described how her partner pulled the condom off and she made him stop. She told him:

You know, I can’t be responsible for that. He was like, “I don’t want to use a condom. I just want to be with you.” I talked with a lot of my girlfriends that are HIV positive and they tell me even though the man knows that they’re positive, they don’t want to use condoms.

Indeed, two thirds of the women who told their HIV-negative partners that they had HIV were unsuccessful in getting these partners to consistently use condoms. Laura described the conflict:

The doctors would tell him, “You need to use a condom,” and he would look straight at them and say, “I’m not going to.” Then they were trying to tell me that I needed to abstain from having sex with him. I would always give in, but at the same time I was heartbroken and would be crying afterwards and say, “I could have infected him. What if I infected him?”

Maggie described a similar experience:

When we first got intimate after I found out, I said, "Hey, we're going to have to use condoms." [He said], "All right." And we used them just that one time. Then he just wouldn't use them no more. I know I have to press him, "You have to use them." After a while, I started feeling down about it because every time we were being intimate, he wouldn't use them. . . . The last time I talked to him about it, I was like, "Look, you're really making me sad and depressed, not using condoms. It's enough that I have to deal with me being infected. Who's to say you're not already infected?"

A few women had, with time, developed the capacity to insist on condom use. Martha, in a committed relationship with an HIV-negative man, described this process:

I know I should use them, so I started to use them and sometimes we'd use them and sometimes we wouldn't. The guilt was there if we didn't use it and then the pain was there if we did use it. If we didn't use it I'd be trying to fool myself into believing that I didn't have [HIV] . . . I could still have wonderful sex and enjoy it, and as soon as it was over I was a mess, because the reality was there again, facing me. . . . He wanted to always prove to me how much he loved me. . . . He wouldn't wear one because he would say, "I don't care. I love you very much." Recently I really put my foot down and I said, "We can't do this anymore. If you want to kill yourself, then you do it in another way. I'm not going to help you. I want to know that I did the right thing."

Sarah, who had several casual relationships, described her development:

In the beginning, my outlook on it was different, and I wouldn't tell. I just had unprotected sex and everything. . . . I still had a lot of growing to do. Here lately, for the last couple of years, when I meet a guy, I tell him straight up, then it's their choice if they want to deal with me or not. . . . Even talking about how I used to do it before without a condom, I feel guilty as hell. And if there was some way I can go back and change it, I would. I always hope that who I dealt with back in those days never contracted this.

Impact of IV Drug Use on Relationship-Linked Issues

The experiences of women who were IV drug users were substantially different from those of women who acquired the virus solely through sexual transmission. It became clear that a history of drug use had an impact on the women's lives and relationships independently of HIV seropositivity, but in such a way as to make the IV drug and heterosexual transmission populations qualitatively and quantitatively different. Although the samples were small, *t* tests comparing the 8 women who reported HIV transmission from drug use with the 17 women

reporting sexual transmission were statistically significant for age, $t = 3.25$, $p < .01$, and income, $t = 2.88$, $p < .05$. Women who had engaged in IV drug use were older ($M = 42.71$ vs. 31.47) and had lower incomes ($M = \$5,545$ vs. \$12,355). Although not statistically significant according to Fisher's exact probability tests, they were somewhat less likely to be involved in a heterosexual relationship at the time of diagnosis (75% vs. 82%), but their partners were more likely to be HIV positive (83% vs. 43%) and they were more likely to have experienced the death of a partner (50% vs. 6%).

Many of the women in the sample reported a period of denial following diagnosis of HIV seropositivity, but for women engaged in drug use, this denial often accompanied continued drug use. Three of these eight women (37.5%) volunteered that being HIV positive served at one time as an excuse to continue using drugs. As Karen explained, "I think that I shared it [her HIV status] because I felt that nobody understood the reason why I was still using drugs. I felt like, I'm HIV positive. . . . I got a reason, because I'm going to die." Sarah said, "When I got out of rehab, I went right back and used all over again because I thought that I was gonna die anyway. So, you know, why prolong it?" Two of these eight women had spent time in jail, and two had been in psychiatric hospitals. All had been in some type of drug treatment program. In addition to dealing with being HIV positive, these women were in recovery from substance abuse. One admitted that she still wanted to "get high"; another attributed her difficulty finding work to her long history of drug abuse.

A history of drug abuse also had an impact on mothers' relationships with their children. Five of these eight women had, at some point, relinquished custody of their children to other family members. Tonya explained, "I think that drug abuse had more of an impact on her [daughter] than the HIV did." Della said:

For all of his [her son's] life, I was a drug addict. He didn't really have me. So now I'm not a drug addict anymore and I'm the best mother that I know how to be. But, you know, I can't make up for that time. And he doesn't say it, but I see the sadness in his eye sometimes. It's like, "I just got my mom back, and now is she going to die on me?"

Relationship Closeness After HIV Disclosure

In response to learning about their HIV seropositivity, women had different reactions in terms of whether they became closer to significant others. Women recalled more experiences where family members (61.5%) and friends (54.5%) drew closer to them after disclosure as compared with relationship partners (30%). Conversely, women were more likely to recall experiences

where their relationship partners withdrew from them (55%) as compared with friends (41%) and family (35%).

Discussion

Women, perhaps more than men, cope with HIV, or other challenges, within the context of relationships (Jenkins & Coon, 1996). The discovery by a woman that she is HIV positive has far-reaching effects on her relationships. With some life-threatening illnesses, women might turn confidently to those close to them for comfort and support. With HIV, many women do not turn confidently to others. Their narratives indicate that relationships can be both helpful and harmful for a woman with HIV. Every woman in our sample had disclosed her HIV status to someone close to her. All had experienced support and caring from some others.

On the other hand, relationships can hurt as well as heal. The most obviously harmful relationship experiences generally occur as a result of the stigmatizing aspects of HIV. Stigma arises from at least two sources: the lifestyle implications of an HIV diagnosis and the infectious nature of HIV. Choosing to whom, when, and how to reveal this information was often stressful, and nearly every woman had experienced moments of uncertainty wondering how a partner, family member, or friend would respond to the information. Nearly all had experienced some form of rejection or restriction owing to others' fears of infection. It is also not always possible to know whether another's negative response is based on disapproval or fear. A woman whose partner abandons her after the diagnosis or who is rejected by a potential new partner may attribute his reaction to either or both. The explicit negative reactions from others are a source of stress. But concern about how others might react is also a source of stress. Many women were reluctant to disclose information about their HIV status because of concerns about what others would think or ask about them. Women are also aware that others may be hurt by their disclosure. Not telling to protect the other is a common reason given by both women and men for not disclosing. When others do know, women often are aware that the stigma of HIV is a burden to them as well. Family members ask that the information not be revealed. These women's children found that others rejected or taunted them.

An additional burden is the worry that others feel about the welfare of the woman with HIV. This is particularly true for the children. Most of these women (59%) reported that they observed their children to be worried about losing their mothers. Women with partners who are HIV negative worry

about the possibility of infection, especially when, as is common, condoms are not used during intercourse. Women who insist on practicing safe sex have the stress of being the person responsible for making sure that condoms are used.

In open-ended questions, Demi et al. (1997) found that women with HIV list "focusing on others" as a coping strategy. This and an emphasis on spirituality were the two ways in which women's list of coping strategies appeared to differ from men's. The potential negative relationship consequences of HIV need to be noted, as these are likely to have an important impact on women. Providing women with help in dealing with their relationships should be a focus of efforts to help women with HIV cope with their illness.

Women also cope with HIV in the context of other life stressors. This was particularly evident in the differences observed between women who had a history of drug abuse and those who did not. These women were poorer, more likely to have relinquished custody of their children at some point in their lives, and (although not statistically significant in this small sample) more likely to have an HIV-positive partner and to have experienced the death of a partner.

Every woman interviewed reported that some relationship in her life had changed as a result of her HIV status. As in past research (e.g., Derlega, Lovejoy, & Winstead, 1998; Simoni et al., 1995), the women in this sample disclosed HIV status to receive social support, protect others, educate others, and to have a chance for emotional release, especially with others suffering the same fate. However, women also chose not to disclose to certain people for fear of rejection, fear of stigmatization, to control gossip, to keep from being a burden to others, and because of feelings of inadequacy and shame.

Despite their worries, many women received social support from others when they disclosed their HIV status. By their accounts, these women found their families to be most supportive in response to their revelation. But even in cases where family members responded positively, there were likely to be some whose responses were negative, including fear and/or withdrawal. Some experience of being stigmatized by family members was also common.

Children tended to demonstrate a supportive response when they learned that their mothers had HIV; most were accepting, loving, and protective. Some even took on the caregiver role and reminded their mothers to take their medications. Mothers, however, perceived their children's fear, anger, or denial and worried about their children's ability to cope with their loss and/or with the stigma of having an infected mother. In fact, many instances of rejection of children by others who knew about the mothers' HIV status were recounted.

Once these women discovered their HIV seropositivity, they entered a social world in which knowledge of this status could change their relationships. This is perhaps clearest in reference to their most intimate relationships with sexual partners. Only four women (20%) partnered at the time they learned their diagnosis were still with their partners at the time of the interview. Having the virus may mean that one's partner also has it, and this was true for 11 of these women (55%); this may mean seeing one's partner become more and more ill and even die, as happened to seven women (36%). On the other hand, having a partner who is not HIV infected may mean experiencing rejection when the woman's HIV status is disclosed, as happened to six women with serodiscordant partners (30%). Entering into new relationships is particularly stressful; half of the women who met men with whom they experienced a mutual attraction were rejected after they revealed their HIV seropositivity. Negotiating condom use with current partners and/or new partners was also difficult; most women found themselves unable to insist on condom use despite feeling concern or guilt about the possibility of spreading the virus.

Women also reported not using condoms with HIV-positive sexual partners because of a belief that, if they were both infected, safer sex did not matter. Because women in our sample had known about their diagnosis for some time, this may be an inaccurate belief that is now less common among persons diagnosed with HIV. The importance of practicing safer sex, even among concordant positive partners, should be a part of all efforts to inform high-risk or HIV-positive populations.

Failure to use condoms, even in situations that they recognized as unsafe, was very common in this sample of HIV-positive women (see also Hunt, Myers, & Dyche, 1999). Even revealing their seropositivity and telling partners to use condoms did not result in consistent condom use. These women were uncertain how to handle male indifference toward or refusal to use condoms; some concluded that it was the man's responsibility and his choice to assume the risk. Others felt guilty but helpless. Only those women who insisted and/or refused to have sex without condoms reported always practicing safer sex.

Confirming Stevens and Tighe Doerr's (1997) findings about the initial reaction to discovering one's HIV seropositivity, most of these women were devastated and thought they were about to die. These findings suggest that agencies offering HIV testing and diagnosis need to provide more extensive education to clients to overcome the image of calamity that HIV evokes. Women said that, later, when they learned more about the disease, they realized they may have years to live, but this was not something many of them learned quickly. The initial panic and pessimism experienced by these women

led to negative consequences, including returning to drug abuse, quitting jobs, and isolating themselves from others.

Limitations of the Present Research

We want to be cautious in drawing conclusions from this study. First, the participants were contacted through HIV/AIDS service organizations, and they may not be representative of other women living with HIV. It is possible that individuals who are the most socially isolated are less likely to seek out these organizations or to have participated in this study. Second, a relatively small number of participants were interviewed for the study. However, the participants matched surveillance report data (CDC, 1999) on the demographic distribution of HIV-seropositive cases among women in the United States, insofar as the majority of the women were infected via sexual behavior and they were mostly women of color. Third, the women provided via self-reports all of the information about their relationships with their children, parents, friends, and lovers. Future research should compare both women's and significant others' perceptions of the impact of HIV on their relationships.

Conclusions

Our research, consistent with earlier studies (Barbee et al., 1998; Ingram, Jones, Fass, Neidig, & Song, 1999), indicates that studies of coping with HIV and AIDS must consider both the positive and the negative ramifications of this disease for close relationships. Although there may be many positive aspects of social interactions that follow disclosure of seropositivity (including accessing social support and bringing relationships closer together), there are also negative aspects (such as the increased possibility of rejection and being the target of gossip). The research also indicates that individuals living with HIV, besides having many personal concerns (e.g., about their health status, effectiveness of medications, severity of illnesses, and financial problems), grapple with concerns about the state of their relationship with families of origin, children, friends, and intimate partners. Many women with HIV were concerned about what their parents and relatives would think about them, what would happen to their children if they were not able to take care of them, and what the chances were of transmitting the HIV infection to sexual partners. On the other hand, these relationships also provided a source of stability in the lives of many of these women.

The present research was exploratory. It suggests several questions for future research. For instance, what are the consequences of positive and negative social interactions in close relationships (with children, parents, friends, intimate partners) for the physical and psychological health of mothers with HIV? What psychological and social resources contribute to maintaining close relationships for women with HIV? How might new medications and medical treatments (with expectations of living longer and, hopefully, with fewer physical symptoms) influence relationship functioning?

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