DISCLOSURE OF HIV-POSITIVE STATUS

FIVE WOMEN'S STORIES*

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Estimates of the incidence of HIV infection suggest women's rates of infection have continued to rise steadily. This qualitative study investigated the factors contributing to 5 HIV-positive women's decisions to disclose or not to disclose their HIV status to family members and friends. Data were analyzed using grounded theory principles, resulting in a proposed model of disclosure that applies to these women. Implications for helping professionals and future researchers are discussed.

The Human Immunodeficiency Virus (HIV), the virus that causes Acquired Immune Deficiency Syndrome (AIDS), is one of the most severe health threats in this country. From June 1981, when the first case was diagnosed, to December 1994, there were over 440,000 cases of AIDS reported to the Centers for Disease Control, with 61,400 or about 14% of these cases women (CDC, 1994). Given that symptomology of women's HIV infection is inadequately researched, it has been suggested that underreporting of HIV infection in women is occurring (Corea, 1992). Regardless, the incidence of HIV infection in women continues to rise steadily. For example, from July 1991 to June 1992, 13.7% of reported AIDS cases were women. This percentage has increased each subsequent year, with women comprising 15% of the total cases from July 1992 to June 1993 and 17% from July 1993 to June 1994 (CDC, 1992, 1993, 1994). Considering that women made up almost 23% of reported HIV infection cases (from states with confidential reporting laws) through December 1994 (CDC, 1994) and assuming that HIV will eventually progress to AIDS, women are likely to constitute an even higher proportion of future AIDS diagnoses.

Although heterosexual transmission accounts for only 3% of HIV infection cases among men, 36% of women with HIV contracted the virus via heterosexual intercourse (CDC, 1994). When women and HIV are discussed, three groups of women are most studied: prostitutes, injection drug users, and women of color (Welch Cline, McKenzie, & Glassman, 1992). Although these subgroups are important populations for research, scientists have typically viewed women in relation to others, primarily their sexual partners and children, rather than as significant victims *themselves* of this epidemic (Welch Cline et al., 1992). Women as transmitters of the disease to men and babies are examined more often in the social science literature than women as victims of the disease (Anastos & Marte, 1989; Cohan & Atwood, 1994; Corea, 1992; Hunter, 1992).

With few exceptions, little research concerning women and disclosure in the context of HIV has emerged. There has been no research examining this issue specifically from the perspective of HIV-positive women, yet understanding women's experiences in disclosing such information is important for a number of reasons. First, disclosure is necessary for support services to be garnered. These services can take the forms of medical information and care, social services, mental health services, and emotional support from family and friends. Without disclosure, an HIV-positive woman may not be able to secure the services and support she wants or needs.

Second, disclosure is necessary to reduce the perpetuation of women as "invisible participants" in this epidemic. Examinations of the role of women in the HIV/AIDS epidemic have been limited to women's relationships with others (e.g., prostitutes, mothers of infected children). For women to continue to gain visibility within the scientific, medical, and social services communities, disclosure of their serostatus must be addressed.

Although the reasons for HIV-positive women to reveal their status are important, women may experience difficulty in disclosing. The sources of these difficulties may be twofold. First, people with HIV are more stigmatized than people with diseases such as toxic shock syndrome or Legionnaire's disease (Hughey, 1986), cancer and coronary disease (Walkey, Taylor, & Greene, 1990), or leukemia (St. Lawrence, Husfeldt, Kelly, Hood, & Smith, 1990). This stigma may center around the perception of AIDS as a gay male disease or its association with activities such as infidelity and injection drug use. Given the possibility of stigmatization, it is understandable why HIV-positive women may choose not to disclose their status.

Second, disclosure of one's HIV status could put women at risk for losing employment, housing, health insurance, friends, or custody of their children. By keeping her status private, a woman minimizes other potential sources of stress (Welch Cline et al., 1992), thereby aiding her physical, emotional, and mental health as an HIV-positive woman.

Given the stipulated costs and benefits of disclosing one's HIV positive status, it is understandable why disclosure can become a central dilemma in the lives of women who learn they are infected with HIV. This research attempts to understand these women's experiences from the perspective of the woman who has contracted the disease. The purpose of this research is to assess factors contributing to HIV-positive women's decisions to disclose or not to disclose their HIV status to family members. In order to better understand this process of disclosure, the research question under consideration for this study was:

> *RQ: What decision making processes do women experience in deciding to disclose or not to disclose their HIV status to family members?*

METHODOLOGY

Sampling

Maximum variation sampling procedures were used to sample potential participants for this study. Lincoln and Guba (1985) note that when investigators seek

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to understand phenomenon "in all of its various ramifications and constructions" (p. 201), it is preferable to sample on the basis of divergence of experiences. The participants for this study were 5 adult women chosen because of their diverse ethnicity (1 Hispanic, 2 African American, 2 Caucasian), mode of contraction (2 from husbands, 2 from either IV drug usage or unprotected sex, and 1 unknown), as well as age (24 years to 42 years). Women living in a medium-sized community located in the southwestern United States were identified and contacted by the Director of Support Services at a nonprofit community based agency that serves HIV-positive individuals. This sampling procedure allowed for a diverse sample and ensured the anonymity of the participants.

Procedures

All semi-structured interviews were conducted in April, 1993 in a clinical setting. Each interview lasted from 45 to 90 minutes and was conducted by the second author, a Caucasian, female clinician. Because these women's process of disclosing their HIV-positive status and the recipients of that disclosure were of primary interest, questions focused on who was and was not told and reasons why. Stimulus questions included, "Who did you tell/not tell you were HIV positive?" "Why was that person told/not told?" "What did you consider or what factors were involved in deciding to tell/not tell this person that you were HIV positive?" Additionally, the actual process of disclosure ("when" and "how" questions) was also examined. Each woman was paid $25 for her participation.

Data Analysis

In order to understand these women's experiences, the data were analyzed using grounded theory procedures, which allow the researcher to develop and understand theory and typologies inductively from the phenomena in question with a focus on processes and interactions (Strauss & Corbin, 1990). For this investigation, four steps were taken to analyze the data. First, interviews were transcribed verbatim, checked for accuracy by the investigators and participants, and edited for identifying information. Next, the interviews were coded for content based on the interview dialogue, with sections pertaining to disclosure to family members being isolated in text. The text was then read and reread by all investigators with the goal of identifying categories, themes, or recurring processes. Lastly, the interviews, as well as the processes extracted by the investigators, were subjected to peer debriefing by a disinterested third party. Here, any biases of the investigators were probed, and the basis for interpretations clarified. This step is congruent with Lincoln and Guba's (1985) suggestions that peer debriefing occur "for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind" (p. 308).

FIVE WOMEN'S STORIES

Although these women's experiences cannot be generalized to all individuals facing this situation, what follows are descriptions of these women's ordeals, thoughts, and feelings about disclosing their HIV-positive status and why they chose the individuals to whom they disclosed. All women's names have been changed to protect their identities.

Ann

Ann is a 38-year-old, divorced Caucasian female whose mode of contraction and time of diagnosis is uncertain. She presented herself as an amiable woman, easily adapting to the setting and using her sense of humor to put herself at ease. Although Ann was given an HIV-positive diagnosis 8 years ago, she believed the original diagnosis was inaccurate and that she actually contracted HIV 1 year prior to the interview. Ann had been a heroin user "on and off" for 20 years, but had also engaged in unprotected sexual activities with other injection drug users.

Ann's initial disclosure was to "nobody" because "the doctors told me I only had a year to live." Ann had not wanted members of her family to know she was HIV positive because they "had been through enough" due to her father's recent death. Specifically, she had not wanted her son to know because she did not want him to "see me die." Ann's reluctance in telling her family changed a few months before the interview and they now know her HIV status. On telling her son, Ann states, "he wants nothing to do with AIDS, or me, or any of it." Her reason for telling him was, "Well, if I die, I don't want him to think I died a coward. We were honest with each other. I didn't feel that there was anything he could do for me right now but I wanted to give him the respect."

When Ann told her mother, her mom responded with ". . . I don't know what you think I can do about it, we've all got our lives to live" and "Well, it's amazing that you didn't get it sooner." Ann was uncertain why she told her mother but she did state she missed "being part of a family." Her disclosure, however, did not bring her the closeness she had hoped.

Ann's sister is also HIV positive. She and her sister "do not get along that well . . . there's no love lost between us." According to Ann, her sister tried calling several times after finding out Ann was positive but "she overdramatizes and I can't. . . . I'm just the opposite. I'll make jokes and, you know, not hurtful jokes, but you know, kidding around, instead of letting the grief totally take me." Ann wasn't sure why or when she told her sister; nevertheless, when her sister disclosed to Ann that she also was HIV positive, Ann reported feeling "hurt" but could not articulate an explanation of that feeling.

Ann's disclosure of her status to those outside of her family is primarily limited to her boyfriend and those persons living within her present community. Ann told her boyfriend "because he's the most important man in my life . . . if I didn't care about him, I wouldn't have." She did not tell her ex-husband because his whereabouts (and serostatus) is unknown. Ann describes her real friends as "hanging in there" when they were told of her HIV-positive status. She stated, "I don't really feel there's anyone I would feel ashamed about telling. I look at it like if they are my friends, this won't matter. If they aren't, I'd rather weed those people out of my life right now."

Ann reflected that one of the problems she has in living with HIV centers around the decision to disclose or not disclose her status to the men she meets: "I also wonder what kind of man would come near me if he knew I was HIV positive. But I wouldn't go with a man unless he knew . . . . it's so ***hard*** to tell somebody that, it's like you know, it has to be an instant turn off for them."

Barbara

Barbara is a 32-year-old, single, African American woman who contracted HIV either engaging in sexual activities with injection drug users or through her own injection drug use. She was diagnosed at a community mental health and rehabilitation facility approximately 6 months before the interview. Throughout the interview, Barbara seemed tense and timid and unable to completely relax.

Barbara's initial disclosure that she was HIV positive was to a friend approximately 2 days after her diagnosis. Barbara told him because she did not fear rejection from him ("he's understanding")

and because her stress level had peaked ("I got tired holding it in. I was about to explode."). In regards to her family, Barbara decided to tell her middle brother first because "he got more sense than all of them [other brothers]." Although she told her brother at his girlfriend's house, Barbara did not tell the girlfriend. Barbara states that the girlfriend "knew something was wrong 'cause he's crying and stuff." It is unclear as to how much time passed before Barbara disclosed her status to her brother's girlfriend, but she eventually did. Barbara relates that they are "pretty close" so she did not feel threatened by telling her.

Approximately 3 weeks after telling her brother, Barbara told her mother. Much of her reluctance centered around her mother's failing health. Her mother had returned home after a stay in the hospital when Barbara told her. Barbara reported guilt about not telling her mother sooner but "she was in the hospital when I find out and I didn't go over there and see her that much and I had this. You know, I had to explain it to her that this was the reason I didn't go see her there." Her mother was surprised, but understanding, and Barbara was relieved that "she accepts me still."

After telling her mother, Barbara told her father. As she puts it, "I'm more close to my daddy than anybody" and disclosed to him because she needed to release some of the stress she was experiencing. She "just had to tell somebody." In addition, Barbara described the need to warn as a reason for disclosing her HIV status to her other brothers. She was afraid they would each contract HIV and thought by telling them "then they'll be careful."

Of her four aunts, only one knows of Barbara's status because she is "closer to her than any of the others." Barbara told this aunt while her mother was in the hospital. Her aunt advised Barbara against telling anyone else of her status, even her mother. Barbara speculates that her aunt's reason for not wanting her mother to know was due to her mother's health. Barbara believed another of her aunt's motivations may have been to protect her. As Barbara stated "with others, I think she [aunt] probably knows how they would accept it."

Of her cousins, Barbara disclosed to one at a birthday party, although they hadn't seen each other in almost 7 years. Barbara's decision was based on her cousin's age, "she the oldest," and her personality, which Barbara described as "understanding." Barbara described the disclosure process as, "[we were] standin', we hugged, and I told her I had HIV." Her cousin cried but Barbara was not certain whether her cousin was crying because it had been 7 years since they had seen each other or if it was because Barbara was HIV positive. Barbara has no children of her own and, at the time of the interview, was not involved in a dating relationship.

Interestingly, Barbara relates that when she is asked by friends, she denies being HIV positive. The exchange is usually couched in terms of "something they heard." Barbara is unconcerned with whether these people find her response sincere but does relate that her friends' actions indicate her HIV status is of little consequence to them because "they aren't afraid to be around me."

Paula

Paula is a 24-year-old, married Hispanic woman who contracted HIV from her husband, Rick. Approximately 7 months prior to the interview, Paula found out she was HIV positive after Rick had been in the hospital with pneumonia and was tested. At the beginning of the interview, she spoke quite softly and often into her hands but, after rapport was established, she visibly relaxed, crossing her legs in the chair and using her hands to gesture for added emphasis.

Because Rick was already HIV positive, Paula "knew I already was, I didn't know how far along, but I knew." Consequently, after her test results came back positive, they told Rick's family together. According to Paula, her mother-in-law's and sister-in-law's reactions were ones of disbelief ("they were just stunned") and fear ("they wanted to get the whole household checked").

Disclosing her status to her two children (a boy 6 years old and girl 4 years old) has been a difficult decision for Paula. Because of their age, to this point, she has told them only that she and Rick are "just sick." She told the children they were ill themselves only so they could be tested. Paula has shown her son videos about HIV and she tells him "little by little how he can contract it and how it's a very serious disease" but not that she is HIV positive. Paula believes she will tell her children "when they get a little bit older" and will tell them together because "she [her daughter] learns as fast as he does now. So she'll mostly know what's going on then because she'll be learning from him."

Paula also related that she had disclosed her HIV status to her mother and sisters the night before the interview but did not tell her father or brother. She will not tell her father because she feels he will not offer her much support. Paula's perception is that his reaction would be ". . . okay, you die, you die. So what?" Similarly, Paula does not believe she will tell her brother because "He's the type of person who really wouldn't care. He'd probably say, 'Well, you've got to die someday.' He's like my dad."

Paula had not told her mother and sisters until the night before the interview because she "just didn't feel they would be supportive in any way or any kind." Paula told her mother for three reasons: (a) "it was about time," (b) she needed support, and (c) she wanted to begin discussing later arrangements for child care once she becomes ill. The precipitating factor the previous evening was the fact that she, Rick, and their children had been living with his family and she had not been receiving the promised support that her mother-in-law said she would provide.

Paula expressed that just telling her mother was "a big chip off my shoulder" and she and her mother decided the next person that should know was her oldest sister, June. Paula relates she called June on the phone and had to convince her she needed to talk about something important. June was reluctant at first and finally asked, "Is this life and death?" Paula replied, "You could say it that way." June then asked if the "issue was on AIDS," to which Paula responded in a vague manner. She reported, "All I heard was a yell across the phone, a scream, I heard crying, dropping the phone, and picking it back up." June said she would be right over. After June arrived and they talked about Paula's health, Paula's mother suggested that June call Paula's second sister, Louise. According to Paula, this was fine because "I felt much better that they all knew at one time . . . instead of finding out one day after another. I did not want to go through the process of having to retell them over again. I wanted to get it over *now*." After Louise's arrival, Paula told her by saying, "I have the news that I'm HIV." Louise's reaction was one of "Oh my goodness, and then saying my name over and over. She couldn't say anything else, she looked like she had gotten torn apart." As for her youngest sister, Mary, Paula does not want her to know because "she has a lot of things to deal with 'cause we just found out that her husband was messing on her. And well, I was like, does she need to know my problems?"

There is only one person outside the family who knows about Rick and Paula's serostatus. Approximately 6 months after her diagnosis, Paula told a friend. Paula's reasons for disclosing to her was that she felt her friend was "more of a [type of] person that would support, which she did."

Carol

Carol is a 42-year-old, married Caucasian woman who contracted HIV from her husband, David. David was hospitalized with what they thought was the flu, at which time blood tests were run and he was diagnosed. Approximately 18 months prior to the interview, Carol was diagnosed. Carol is a vivacious and gregarious woman and freely explained her situation and feelings without reservation throughout the interview.

Much of the disclosure of Carol's HIV status was done in conjunction with the disclosing of David's status. The first people they chose to tell were Carol's mother and sister, Sue. Carol relayed that she called her mother and sister and told them over the phone that David had been diagnosed with AIDS and that she was being tested the next day. After Carol received her results, she said her mother and sister came by the hospital to see David and she was able to tell them in person. At that time, Carol requested that they have her included in a prayer chain they had initiated on David's behalf because "I wanted their prayer cover directly, specifically, for that [her being HIV positive] as well." Carol also called two pastors and "various national and international folks to get a significant amount of prayer cover." As she put it, "literally within an hour, thousands and thousands of people had been contacted" and she had no reservations about so many people knowing.

Carol's half sister, a missionary, was not contacted right away because she could not be reached. In addition, Carol's first ex-husband does not know of her status as they have not been in contact since 1976. She reported, "I don't know of any reason to tell him. We just don't have any kind of a relationship." Carol's second ex-husband does know she is HIV positive. He was told shortly after her diagnosis because Carol was staying with him while David was in the hospital. Carol's reason for disclosing to him was because his family owns a pharmaceutical company that has a research and development department and she hoped he could persuade the company to research HIV.

Carol's aunts and uncles also know of her status. As for her daughters (ages 22 and 19), both Carol's mother and sister told each of them. Carol related that, at that time, because she was with David at the hospital providing his care, she only made one attempt to call her youngest daughter who was away at college. Similarly, her oldest daughter was living out of town and did not have a telephone, so they waited until she contacted Carol's mother to tell her. Carol's father was deceased at the time of her diagnosis.

As for their son, Mark (age 8), Carol and David sat down together and told him because they wanted him to be tested and because "we've always been very honest with our children about the real world they have to live in." They also wanted him to be involved in choosing his caretaker in the event they should become ill. Carol stated that the process of disclosing to Mark went like this: "Honey, you know how sick daddy has been and you know that the doctors couldn't find out what was wrong. Well, they finally thought that we should have an AIDS test made. And we did and the results have come back positive. Daddy has AIDS and momma has been tested and it's what they call HIV positive and that's the virus that causes the condition AIDS."

Carol did relate that if she could do it over again, she would tell Mark in the same way but not keep him isolated from David as much as she did. She commented, "I didn't want Mark to witness the deterioration that was obvious. It frightened him. It was more frightening not to be there. Not to have time with his dad." After they told Mark, Carol went to his school and disclosed her status to the principal and asked him to tell the school nurse and Mark's teacher.

Linda

Linda is a 33-year-old African American woman who contracted HIV from an unknown origin a year before the interview. She looked physically tired and apprehensive about being interviewed. At the time of the interview, Linda was unemployed and living with her boyfriend, son, and grandchild.

Linda was tested for HIV by the health department after seeing a doctor for nausea. Initially she kept the news to herself, "I'm hopin' and prayin' like it's not what it was" while a retest was done. After the confirmation came back she still told no one because "I tried to deal with it myself at first." It wasn't until a month had gone by that Linda decided to tell her 18-year-old daughter and 19-year-old son. Her reason she explained was "I guess 'cause they understand a lot of stuff. You know they read, they can read better than I can." The need for more information about AIDS/ HIV was the reason Linda, 3 months later, told her youngest sister and brother-in-law. She was frustrated with the health department and could not read well enough to understand the pamphlets that were provided; as she stated, "They coulda explained it better than what they did."

The desire for more information was intertwined with a need for support and someone with whom to talk. Linda reported that her younger sister was the one closest to her, although she also considered her aunts to be very supportive. This need for support was what motivated her to tell all her aunts. "I had to [tell aunts and sister] cause, like I said, it was killin' me. I was gonna have a nervous breakdown. I jes' had to have somebody, someone to talk to."

Although Linda had a boyfriend, it was difficult for her to tell him. She recalled that she left her boyfriend with no explanation and refused to see or talk with him for 2 or 3 weeks. She explained that it was "cause I didn't know how to tell him." During their time apart, he continued to call and visit her sister trying to find out why she left him. One night she was at her sister's house when he showed up so she told him. He responded well to the news and "he still wanted me to come back."

Linda chose not to tell her mother, brother, older sister, baby grandchild, and 12-year-old niece. Although she wanted her mother to know, her mother was in poor health and in the hospital with heart trouble. Linda reported that one of her aunts told her mother and her mother confronted her but she denied being HIV positive: "I jes' didn't know how to act. 'Cause I don't know how to tell her nothin' like that. You know, when the time come or somethin' she'll know but other that, jes' me tellin' her, I don't think she need to know." There were also people Linda felt should not be told. Her brother and sister lived out of town and could not help her so there was no reason to tell them.

DISCUSSION

Despite the unique situations for each woman, commonalities exist; the following model (see Figure 1) provides a framework for understanding the disclosure processes of these women. Each step of this six-step process brings its own special dilemmas, barriers, and decisions. Although this six-step process is based on the disclosure patterns of only 5 HIV positive women, over 60 disclosive episodes were discussed during the course of these women's interviews. Therefore, although still exploratory, the process outlined here can serve as a beginning framework for understanding and assisting women with disclosure. Additionally, this model can be helpful for therapists, social workers, medical personnel, family members, or friends who

work with and struggle to help these women. This knowledge is especially important because it is realistic to expect that, as this epidemic continues, women will be increasingly affected and infected (CDC, 1994; Shayne & Kaplan, 1991).

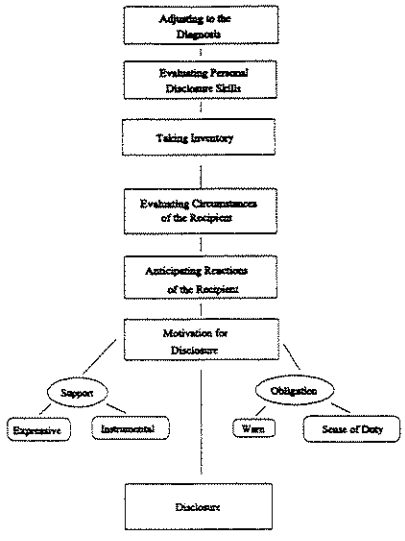
The following section describes each step and proposes therapeutic interventions for each. It should be noted that, although these steps are presented in a linear fashion, there is no reason to believe women experience them in such a strictly uniform manner. In fact, some women may go back and forth between steps and some steps might not be experienced at all.

Step 1: Adjusting to the Diagnosis

For these women, the first step of the disclosure process was adjusting to the shock of their diagnosis. These women needed time to make personal adjustments to their diagnosis before telling others. As Linda remarked, "I tried to deal with it myself at first." Four of the 5 women in this sample reported they told no one initially after receiving their diagnosis.

After a period of struggling with the diagnosis themselves, these women came to a place in which they could begin thinking about telling others. Although this time varied in length, it usually coincided with the time between testing and retesting or between a partner's diagnosis and her own test results. For example, those women who were married and received their diagnosis after their husbands were diagnosed had a period of time where they could begin thinking about their own serostatus and how to tell others. This window of time may have served as a psychological buffer for these women in that they were already contemplating the possibility of being HIV positive. As Paula stated, "I already knew I was [HIV positive], I didn't know for how long, but I already knew." For those women who were not tested because of their partner's diagnosis, this buffer period did not exist and, therefore, reaction to the diagnosis took a different form.

Figure 1. Process of disclosure.



Interventions. At this step of the disclosure process, interventions might include aiding women in adjusting to their diagnosis and reaching a level of personal acceptance. For some women, adjustment might be facilitated by interventions such as support groups or crisis counseling. For others, this time might involve additional education about the disease and/or information about available services.

Step 2: Evaluating Personal Disclosure Skills

After these women reached some level of being able to deal with the diagnosis, the next step was an examination of whether they possessed the skills necessary for telling others. Here, these women evaluated their ability to disclose relevant yet disconcerting information. This process is evidenced by reports of apprehension about not knowing how to approach the subject. For example, Linda stated she had not told her mother because "I jes' didn't know how to act. . . 'Cause I don't know how to tell her nothin' like that."

Interventions. A reaction such as Linda's speaks to the need for HIV-positive women to be counseled on strategies for successful disclosure. Programs might be developed to educate these women on pros, cons, difficulties, and strategies for both telling family members and having their own needs met. Such programs might include role plays, support groups, or discussions of successful/unsuccessful approaches to disclosure utilized by other women.

Step 3: Taking Inventory

The next step in this process is evaluating the appropriateness of disclosing to a potential recipient. This process encompasses taking inventory of one's family and friends network and deciding, seemingly on an individual basis, whether that person should be told. Criteria for evaluation centered around the person's role (family, nonfamily) and the level of social distance (intimate, nonintimate). For example, Barbara stated she did not tell some people because "it was none of their damn business." For most of these women, family members were considered appropriate recipients, whereas nonfamily members, such as persons in the community, were considered less appropriate. This classification supports previous research findings (Serovich & Greene, 1993; Serovich, Greene, & Parrott, 1992), which suggest that individuals create informational boundaries concerning appropriate recipients of disclosure and that the relationship quality and anticipated response are significant predictors of disclosure of HIV testing information (Greene & Serovich, 1994).

Interventions. Deciding whether to disclose to others can be one of the most difficult processes for HIV-positive women. Women may need assistance in defining their family boundaries or appropriate recipients of HIV testing information in order to help reduce the potential stress arising over such decision making processes (Stulberg & Buckingham, 1988). It is important to note, however, that because individuals create boundaries on an individual basis, decisions about who to tell and who not to tell are idiosyncratic. In addition, women need to be informed of the legal rights of HIV-positive persons and laws surrounding HIV disclosure. For example, state laws vary as to whom the disclosure of HIV testing information is required. Thus, although it may be morally correct to disclose to one's partner, it may not be a legal requirement. In fact, in most states, partner notification programs exist in order to confidentially inform past partners of potential risk (For a comprehensive review of state laws, see Campbell, 1990; Hermann & Schurgin, 1991).

Step 4: Evaluating Potential Recipients' Circumstances

In this phase of the disclosure process, these HIV-positive women evaluated the circumstances that might prohibit disclosure. At this point, someone may be deemed appropriate, but circumstances surrounding that person prohibit disclosure. For instance, for the women in this study, prohibitive circumstances included poor health, the age of the person to be told, whether the family member was enduring a crisis him/herself, and physical proximity.

Except for Carol, none of the women who had children or extended family members (usually nieces and nephews) under 13 years of age told them they were HIV positive. These women told children that "they were sick" or "may not feel well a lot of the

time" but none actually stated she was infected with HIV. These women stated that because they were unsure if the children were able to understand the information adequately and correctly, the decision was made to reveal only that they were sick.

Some family members were not told because they were experiencing personal difficulties themselves or were experiencing health problems. For example, Paula did not tell her youngest sister because she "has a lot of things to deal with." In talking about her son, Ann related "I didn't feel there was anything he could do for me right now . . . 'cause he was going through a lot of trips behind my dad dying."

An additional circumstance that may prohibit disclosure is distance. If a family member lives far away, he or she may be unable to provide the support desired by the discloser. For example, because Linda interpreted distance as unavailability, she saw no reason to tell her brother and sister.

Interventions. Interventions at this step may focus on two options. First, women may need assistance in accepting that some friends and family members may never know about their illness. It is plausible that this situation may arouse feelings of guilt for not telling them and fear or anxiety that others may find out anyway, as well as sadness or anger in not being able to share this information and garner needed services or support. In this situation, women may need assistance in either processing and accepting the situation or making different choices. Second, women may need to develop plans for later disclosure when children are older, people are healthy, crises have been resolved, or the person is closer in proximity.

Step 5: Anticipating Reactions of the Recipient

Anticipating the reactions of the potential recipient of this information is the next factor in predicting whether or not these women disclosed. Here, these women tried to foresee how the person would respond to being told she was HIV positive. Anticipatory reactions took three forms: supportive, hostile, and ambivalent. Most of the women even experienced a period of "testing the waters" with someone they knew would be understanding. For example, Paula told her friend, "you look like you can support me until I tell my sisters." These women also related that telling people whom they anticipated would be understanding made it easier for them to tell others. Once the process began and they received support, it was easier to tell others. For example, Paula, in trying to decide whether to disclose to one of her sisters, asked her a lot of questions regarding HIV "to see how she'd deal with the situation when I did tell her." It should be noted that those people whom the women anticipated as being supportive were still cautiously approached because of the inherent risks involved with disclosing this information.

Women elected not to disclose when a hostile reaction was predicted. Paula stated that initially she did not want to tell members of her family because "I thought they would have rejected me because of the way we grew up and stuff." She also related that one of her sisters was not considered as a caretaker of her children because her husband was "the type that doesn't really understand the disease yet. He's like, you have it—you gotta get away from me." Other women feared not having a romantic relationship and wondered, as Ann did, "what kind of man would want to come near me if he knew I was HIV positive?" Additionally, when it was anticipated that a person would react ambivalently, she or he was not told. Exemplary of this is Paula, who did not tell her father or brother because "[they] aren't the type of person who would really care."

Interventions. At this step, women may need to work at clarifying anticipated reactions. For example, processing how the person responded to sensitive information in the past may be useful. Similarly, coaching women in ways to "test the waters" and how to clarify whom they may be able to ask for help is also relevant here. Deciding that some individuals may never be told or may be told later may also be appropriate.

Step 6: Motivation for Disclosure

The final step in these women's decisions to disclose was their motivation for disclosure. Here, if they had decided that disclosure to a particular person was appropriate, the women still had to have some motive to disclose their status. For these women, motivation took two forms: support and obligation. Support included expressive needs, such as the cathartic nature provided by telling, and instrumental needs, such as acquiring accurate disease information and care for children. Obligation included a sense of duty and a desire to warn or help the person.

The most prevalent motivation for disclosing their serostatus among these women was the need for expressive support. Comments such as "I got tired just holding it in. I was about to explode" and "I was goin' crazy and had to tell someone" reflected the importance of needing to share the burden. As Linda clearly stated, "I was gonna have a nervous breakdown. I jes' had to have somebody, someone to talk to."

These women also needed to disclose to acquire instrumental support. This support took two forms: care for children and information about HIV. Paula and Carol, both of whom had young children, told family members in order to secure caregiving for their children when the women got sick and after they were gone. Not surprisingly, each discussed the issue of her children's welfare with other family members, primarily female siblings. Carol revealed that she and Rick had gone through a list of possible family members and crossed them off one by one in attempts to agree on who would be the best caretaker. Before this could be done, however, they felt that each family member had to be told and agree to care for the child.

Some women reported that disclosing was necessary to obtain additional information about HIV. Linda stated that she disclosed to her older children and youngest sister so they could give her information because "they can read better than I can." Carol remarked that she "wanted every drop of information that anyone had about it. I was like a little sponge, just sucking it up and assimilating everything."

Another facet of motivation for disclosing their HIV status was a sense of obligation to tell their family members. This obligation was manifested in two ways. First, there was a need to protect their family members. For example, Barbara felt that by disclosing her status to her brothers "maybe they'll be careful." Secondly, disclosure occurred out of a sense of duty. Ann stated that her reason for disclosing to her son was that she "wanted to give him the respect" of knowing.

Interventions. At this point, a woman may need to identify persons best suited for meeting her instrumental and expressive needs. For example, a woman may need to identify those persons whom she might rely on for emotional support. This process of clarifying her needs and identifying who might best meet them serves two purposes. First, this process can assist women in clarifying what they hope to attain from the disclosure. Second, it can help women establish that the persons are appropriate sources for meeting identified need(s). Women may also need a time for preparing themselves in the event that

the recipient is unable or unwilling to be of assistance.

IMPLICATIONS FOR EXPANDING THE MODEL

There are a few concluding points and caveats that need to be made about the applicability of these findings. First, because these women were open enough about their HIV status to seek assistance from the agency from which they were recruited and were willing to be interviewed, this sample is inherently biased. Therefore, it is of primary importance that these findings be placed in the context of the women interviewed. The described process may not be adequate for explaining the disclosure processes for the multitudes of persons that are affected by this disease. That is, factors such as gender, age, income, race/ethnicity, social class, mode of contraction, sexual orientation, and the nature of the relationship may influence the utility of such a model. For example, Crandall (1991) found the women who had contracted HIV from heterosexual sex reported feeling more stigmatized than the men who had contracted HIV through homosexual sex. This further suggests that the applicability of this model to hemophiliacs, adolescents of either gender, gay men, lesbians, or heterosexual men may be limited.

In addition, these women did not address disclosure to nonintimates, such as employers, landlords, coworkers, or bank tellers, even though the nature of the interview did not impose such a restriction. Future researchers might consider exploring the disclosure process for women to nonfamily members.

Second, there is no theoretically proposed time requirement or restrictions for movement through the steps. For some women, as in the case of Carol, the stages may be moved through quite rapidly. Other women, however, might take considerable time in making decisions. What remains important is that women be able to identify where they are in the process, feel good about where they are, and be assisted in taking steps at a pace that feels comfortable.

Third, the interventions discussed here are proposed in reaction to the women interviewed for this research. The goal of these suggested interventions is to help women find the path to disclosure that maximizes their support and fulfills their needs. The proposed interventions are not exhaustive and, therefore, helping professionals are encouraged to be creative in developing therapeutic programs, procedures, and interventions that most fully meet the needs of the women with whom they work.

Next, it is hoped that the ideas expressed here will provide future researchers with diverse avenues for exploration into the lives of HIV-positive women. What interventions and strategies are most effective at different steps of the disclosure process? How are the various steps managed most effectively? More specifically, how do women disclose to their children? Does disclosure vary by age of the child and what is the corresponding reaction by the child? What coping strategies do the women employ? What strengths of HIV-positive women will assist with their survival? These questions are especially meaningful in the facilitation of medical care and maximization of the quality of life for HIV-positive women because such research may predict women's willingness to seek medical services, social service support, and therapy.

Lastly, this research has implications and applicability for women in general as they struggle with other stigmatizing information. For example, it would be expected that mothers of HIV-positive children might experience a similar process to those who are infected themselves. Is the model, then, congruent with the experiences of women who face disclosing information such as rape, abortion, or sexual abuse? Future researchers might test this model with larger and more diverse populations of women who struggle with various secrets that burden and subsequently oppress.

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