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Disclosure of HIV infection: how do women decide to tell?

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Abstract

This descriptive study explores the phenomenon of disclosure of HIV infection by women. Specifically, we examined women's level of disclosure to various groups and how these disclosure decisions are made. The sample consisted of 322 HIV-infected women residing in the southern US. Participants were predominantly African-American, single women of reproductive age with yearly incomes less than $10 000. Data were collected at the first interview of a longitudinal study of reproductive decision making. Findings showed that the majority of the women had disclosed to some sex partners, close family and friends, and health care professionals. However, for a group of women, disclosure of HIV infection is a difficult issue supporting the need for health education and counseling. Qualitative data were analyzed using content analysis and revealed three major categories describing how women make disclosure decisions: full disclosure, criteria for disclosure and emotional disclosure. Quantitative analysis revealed few demographic differences among women in the three disclosure categories. These findings provide insight that can assist those working with HIV-infected women in helping them decide not only to whom they disclose, but how best to disclose.

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Introduction

HIV infection among women of the US has increased exponentially over the last two decades, particularly among women of color. In 1982, only 6% of AIDS cases reported to the Centers for Disease Control and Prevention (CDC) were in women (CDC, 1982). According to the latest statistics from the CDC, women of reproductive age account for 23% (119 810) of all AIDS cases reported (CDC, 2000). While African-American and Hispanic women comprise only one-fourth of all US women, they account for 77% (92 360) of AIDS cases among women (CDC, 2000). HIV/AIDS remains the third leading cause of death in African-American women of reproductive age (CDC, 1999).

More people are living with AIDS in the South than any other geographical region of the US (CDC, 2000). HIV disease has spread rapidly into rural communities (Lam and Liu, 1994; Lansky *et al.*, 2000). Access to health care professionals and to resources in rural areas is limited, particularly for HIV-related health care needs (Lishner *et al.*, 1996). Rural women's fear that others in their community might learn of their HIV infection was second only to having HIV disease itself (Sowell *et al.*, 1997; Heckman *et al.*, 1998).

Learning that one is HIV-infected creates an internal struggle about whether or not to disclose one's HIV-seropositive status (Marks *et al.*, 1992). The decision to disclose is selective and consists of

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several steps, including adjusting to the diagnosis, assessing one's disclosure skills, deciding whom to tell, evaluating the recipient's circumstances, anticipating the recipient's reaction and having a motivation to disclose (Kimberly *et al.*, 1995). The decision to disclose one's status is a difficult one, and must include to whom, when, where and how to reveal one's status to others. The decision to tell one's family members may be especially difficult (Kimberly *et al.*, 1995; Serovich *et al.*, 1998).

Disclosure of sensitive information is generally thought to have beneficial effects on an individual's health (Pennebaker *et al.*, 1990). First, disclosure is believed to lower stress levels and ultimately lead to better psychological health (Pennebaker *et al.*, 1990). A certain level of disclosure is necessary to access AIDS-related health care resources. HIV-infected individuals who disclose their seropositive status have been found to make fewer physician visits and have better immune functioning (Pennebaker *et al.*, 1990). Choosing to disclose may result in less social isolation, and facilitate accessing social support, health care and social services (Cline and Boyd, 1993).

Disclosure of one's HIV status to sexual partners is essential in stopping the spread of HIV infection (Kalichman and Nachimson, 1999). Over 20 states have enacted laws making it a criminal offense for an HIV-infected individual to fail to reveal to a sex partner that he or she is HIV-infected (Lisko, 1998). Yet, many HIV-infected individuals do not disclose to all sex partners. Kalichman and Nachimson concluded that HIV-seropositive women have greater difficulty disclosing their HIV status to sexual partners than do men (Kalichman and Nachimson, 1999). Previous research on disclosure to past or current sex partners demonstrates that between one-fourth and one-half of those with HIV have not told their sex partners. (Stein *et al.*, 1998; Kalichman and Nachimson, 1999).

In spite of the proposed benefits of disclosing one's HIV status, choosing to disclose may leave a woman open to stigma and discrimination and put her at risk for loss of employment, housing, health insurance and custody of her children (Kimberly *et al.*, 1995). Additionally, disclosure does not always bring relief and that disclosure may be accompanied by regrets (Levy *et al.*, 1999). Hays *et al.* concluded that among the costs of disclosure are an ego that is hurt and a self-confidence that is lowered (Hays *et al.*, 1993). A number of researchers have reported that disclosing one's HIV-seropositive status more often leads to stigmatization and discrimination than to social support (Gerbert *et al.*, 1991).

Further, disclosure may lead to disruptions in interpersonal and intimate relationships (Black, 1993; Yep, 2000), abandonment and rejection (Mooney *et al.*, 1992; Black, 1993), and discrimination (Yep, 2000). Disclosure of HIV infection by women may present unique risks. A woman's disclosure of her own HIV status may lead to stigmatization and discrimination of her children (Moneyham *et al.*, 1996). Simoni *et al.* found that one in five women who disclosed her HIV to her partner was abandoned (Simoni *et al.*, 1995). A woman's disclosure of her HIV infection to sexual partners may trigger violent episodes (Rothenberg and Paskey, 1995; Zierler, 1997; Zierler *et al.*, 2000). Gielen *et al.* found that one-fourth of women in their study had experienced negative consequences of disclosure that included rejection, abandonment, and verbal and physical abuse (Gielen *et al.*, 1997).

Lazarus and Folkman's theory of stress and coping provides an appropriate physiological perspective for the current study (Lazarus and Folkman, 1984). This theory proposes that a person's cognitive appraisal of a situation or event will determine if that situation or event is viewed as a threat, as well as determine the person's response. Stress theory indicates that a person's view of the world and their assessment of how they are able to respond to difficult situations is critical for successful coping (Lazarus and Folkman, 1984; Lazarus, 1991). Because of the stress associated with disclosure of HIV infection, women's ability to effectively cope may be strained, especially in the context of a relationship where the women may be at risk of pregnancy. While it may be necessary for women to disclose their HIV infection to obtain needed resources and support, nega-

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tive consequences may be associated with such disclosure. Therefore, women's decisions related to disclosure of their HIV status (e.g. if to disclose or how to disclose) are likely to be influenced by their appraisal of the positive or negative consequences of disclosure.

Clearly, to provide quality health care and support services to HIV-infected women greater understanding needs to be gained as to how women make decisions related to disclosure, and what interventions by health providers and educators will be most helpful to women in making the decision to disclose. Therefore, the primary purpose of this study was to explore the processes HIV-infected women use to make disclosure decisions focusing on their cognitive assessment of the disclosure event. Secondly, the study sought to identify the characteristics of women who disclosed and at what point this disclosure took place following their HIV diagnosis. Third, differences between types of disclosure and to whom the women disclosed.

Method

This paper reports baseline data focusing on issues surrounding disclosure collected in the first of four interviews for a 3-year longitudinal experimental study (Southern Women's Health Project). The overall purpose of the larger study was to examine reproductive decision making and factors influencing decisions to take AZT to decrease perinatal transmission in a group of HIV-infected women. This study was reviewed and approved by the University of South Carolina, Institutional Review Board. Questions related to disclosure were developed based on our previous research with HIV-infected women (Sowell *et al.*, 1992) and insight gained from a series of seven focus groups with women in the formative phase of the larger quantitative study.

Sample

The sample consisted of 322 women recruited from 12 public health clinics and AIDS Service Organizations (ASOs) in one of three states—Georgia, North Carolina and South Carolina. The health clinics and ASOs provide a range of HIV/AIDS-specific services including HIV antibody testing and counseling, early intervention, case management and primary care treatment of persons across the continuum of HIV disease. Women in the study were of reproductive age and were physically able to become pregnant by self-report. All women in the study were HIV-seropositive based on HIV antibody testing that had been verified by the cooperating agencies. Data for the current analysis (Interview 1) were collected over a 17-month period in 1998–1999.

Procedure

Potential participants were made aware of the study through notices (flyers) placed in cooperating clinics or ASOs or by case managers and social workers working in these agencies. Women who expressed an interest were put in contact with female research assistants who were assigned to each of the cooperating agencies. The purpose and procedures of the study were explained to each potential participant. For those women who indicated a desire to take part in the study, a brief screening questionnaire was used to insure that the women met inclusion criteria. Participant selection criteria included: (1) verified HIV-seropositive status, (2) 18–48 years of age, (3) able to become pregnant (did not have an IUD or had not been sterilized), (4) not currently pregnant, (5) no evidence of dementia and (6) English speaking. All women who met study criteria were asked to participate.

Once it was established that women met the inclusion criteria and wanted to take part in the study, an appointment was made for conducting the interview. Some women preferred to complete the interview immediately. Other women expressed a desire to set up an appointment for the interview (usually within 1 week) giving them time to make arrangements for things like child care or to work around appointments or job responsibilities. Study interviews were conducted at the cooperating clinics/ASOs or at another mutually agreed upon site that provided both privacy and comfort for

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the participants. Following informed consent, all questions were read to the participants and their answers were recorded verbatim. Interviews lasted approximately 2 h and women were paid $40.00 for their participation.

Measures

Women participating in the study were asked to complete a demographic questionnaire designed specifically for the study. Participants were asked to provide their age, race, marital status, education, religion, employment status, income and type of community in which they lived (i.e. urban, suburban or rural). Additionally, participants were asked to report their total number of children, number of pregnancies and children since being diagnosed with HIV infection. Participants were asked to identify their status of illness either as asymptomatic HIV, symptomatic HIV or AIDS. Stage of illness was verified using reported CD4 counts and symptoms reported in other sections of the questionnaire, with women with CD4 counts below 200 being classified as AIDS (CDC, 1992).

To examine issues surrounding disclosure of HIV status, women were asked to respond to a number of short-answer questions and an open-ended question. Women were asked to indicate who was the first person they had told they were HIV-infected. Choices included husband/partner, parents, siblings, children, other relatives, friends or other. For the 'other' category, space for women to identify 'other' was provided. Additionally, a category 'have told no one' was included. Also, women were asked to indicate how long after learning they were HIV-infected that they disclosed to this first individual. A third question asked women if they had told their current partner that they had HIV. Following this question, women responded to nine items asking them to how many people from specific groups they had disclosed their HIV status. These groups of individuals included (1) bosses/employers, (2) close friends, (3) casual friends, (4) parents, (5) brothers and sisters, (6) children, (7) other relatives, (8) health care providers, and (9) sex partners. Response choices were 'none', 'some', 'all' and 'not applicable' (i.e. if they did not have a current sex partner, children or living parents). Finally, women were asked to describe, in their own words, how they decide to whom they reveal their HIV-positive status. Women's responses to this open-ended question were transcribed verbatim into a text file.

Analysis plan

Responses provided on the demographic and short answer questions were analyzed using frequencies, means and SDs. Women's responses to the open-ended question, 'How do you decide whom to tell about your HIV infection?', were analyzed and interpreted using content analysis (Berg, 1989). Of the 322 women participating in the study, 265 (82.3%) women answered the open-ended question. Because most responses were short (33% with nine words or less, 41% with 10–19 words and 26% with 20 or more words), a complex linguistic analysis was not possible. Word counts were conducted for a small number of key terms identified by the researchers, 'need to know', 'confidentiality' and 'trust'.

Each of these women's statements was thematically categorized by two research team members independently. The research team reviewed the thematic categories and three main categories describing approaches to disclosure of HIV-seropositive status emerged. After reaching consensus on the definitions of these categories, the researchers independently coded each response into one of the categories. While clear categories emerged from the data, categories were not completely independent and overlap among categories did exist in 14 of the descriptions provided by the women. The researchers scrutinized these 14 responses and categorized women into one category that best fitted their response. Thirty-four responses were designated non-codable, and these responses included statements in which it was unclear that disclosure had occurred ('I don't feel comfortable telling somebody else'), where disclosure happened due to a third party telling ('Others found out by going to the doctor with me and from other family members. I have not told anyone by myself') and where the participant was

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uncertain ('I don't know'). Twenty-three women gave no response to the question.

Based on the initial coding, agreement between the two researchers was obtained for 233 (88%) of the 265 codable responses. The researchers again scrutinized these cases until consensus was reached regarding what single category to which the 32 cases would be assigned. Coded responses were added into the quantitative data set and ANOVA, χ^2 and Pearson's correlation analyses were conducted to identify: (1) demographic differences between those who had a codable response and those who did not have a codable response, (2) demographic differences based on disclosure category, and (3) differences between disclosure categories and the quantitative questions on 'who the women disclosed to'.

Results

The demographic characteristics of the participants reflected those of women with HIV infection who receive services in the clinics and agencies from which they were recruited (Table I). Study participants were predominately African-American (88%), single (79%) and residing in towns or urban areas (59%) with annual household income less than $10 000 per year (64%). Participants ranged in age from 17 to 48 years with a mean age of 32 years (SD = 7 years). Two-thirds of the women (67%) had a high school or greater education. Participants represented women across the continuum of HIV disease in that 59% were asymptomatic, 26% were symptomatic and 15% had been diagnosed with AIDS. Forty-four (15%) of the women currently lived with a partner or spouse who was HIV-infected. Two-hundred and fifty-nine women (81%) reported having children with the number of children ranging from 1 to 7.

Most women initially disclosed their HIV status to at least one parent, followed by their husband, siblings, friends, other relations and children (Table II). Only 12 (3.8%) women said they had disclosed to no one. The vast majority of these initial disclosures (234, 78.3%) were done within the first week after being diagnosed with HIV infection.

Table I. *Selected demographic characteristics of the sample (n = 322)*

Characteristic	*F*	%
Race		
African–American	266	88.4
other	35	11.6
total	301	
Age (years) [mean = 32 years (SD = 7 years)]		
15–27	89	27.6
28–32	67	20.8
33–39	111	34.5
40–48	55	17.1
total	322	
Marital status		
partnered	68	21.2
single	253	78.8
total	321	
Education		
less than high school	105	32.8
high school graduate	115	35.9
some college	74	23.2
college graduate	19	5.9
graduate school	7	2.2
total	320	
Religion		
Baptist	174	54.4
Methodist/AME	29	9.1
other Protestant	58	18.1
Catholic	16	5.0
Muslim	5	1.6
none/other	38	11.8
total	320	
Annual household income ($)		
<5000	106	32.2
5000–9999	110	33.3
10 000–19 999	71	21.5
20 000–29 999	24	7.3
>30 000	19	5.7
total	330	
Social services received[a]		
unemployment benefits	301	97.7
WIC	244	78.2
AFDC	242	77.3
SSI/SSD	164	52.6
food stamps	157	50.0
Residence	131	40.7
non-urban	191	59.3
urban	322	
total		
Stage of disease		
asymptomatic	190	59.2
symptomatic	82	25.5
AIDS	49	15.3
total	321	

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Table I. *Continued*

Characteristic	*F*	%
Anyone close die of AIDS[a]		
husband/partner	14	8.3
child	6	3.6
parent	7	4.1
sibling	14	8.3
other relative	33	19.5
friend	88	52.1
Number of children		
0	61	19.1
1	38	30.6
2	80	25.0
3	46	14.4
4 or more	35	11.0
total	260	
Pregnancy since HIV-positive diagnosis		
yes	128	40.0
no	192	60.0
total	320	
Employment status		
unemployed	212	66.2
part-time	61	19.1
full-time	47	14.7
total	320	

[a]The numbers are those women answering 'yes' from the base sample of 322.

Table II. *Selective characteristics of disclosure*

Variable	*F*	%
Who was the first person you told you were HIV-positive?		
husband	74	23.6
parent	103	32.8
sibling	39	12.4
other relation	24	7.6
friend	36	11.5
son/daughter	14	4.5
other	12	3.8
no one	12	3.8
total	314	
How long after you learned you were HIV-positive did you tell him/her?		
same day	172	57.5
1–7 days	45	20.8
8–30 days	30	9.7
31–90 days	22	3.0
91+ days	25	9.0
total	294	
Told your current partner you are HIV-positive?		
yes	213	67.8
no	25	8.0
don't have a current partner	76	24.2
total	314	

[a]The percentages are based on valid cases, excluding missing data.

Of the women who had a current partner, only 25 (8%) had not disclosed their status to that partner. However, in the later question about disclosure to specific groups, only 65.4% of the women reported that they disclosed their status to all of their sexual partners (Table III). Fully 86.5% of the women responded that they told all of their health care providers that they were HIV-infected and 9.6% had told some. Almost 60% of the women reported telling all their parents and siblings, 43% all their children, and 23% all their other relatives. Only 3% of the women had told all their close friends and 8% had told all their casual friends; yet, 61% had told some of their close friends and 30% some of their casual friends. Of those women who had 'bosses', a total of 28% of women had told some or all of them.

Three main categories emerged from the qualitative data analysis: full disclosure, emotional disclosure and criteria for disclosure. Thirty-three (12.5%) of the 265 responses fell under full disclosure, 130 (49.0%) criteria for disclosure and 102 (38.5%) emotional disclosure.

Full disclosure

Descriptions of full disclosure ranged from overt responses such as 'That's my introduction when I first meet someone. I say, 'Hello, I am...and I have AIDS'' and 'I'm not ashamed of my disease' to more circumspect descriptions such as 'I don't decide at all. I tell them all when I'm ready'. Some women said, 'I just come out and tell them', 'I tell everyone' or 'Just look up at the Lord and begin to talk'. One woman reported she got pleasure from disclosing in that she was able to help others potentially avoid getting HIV. She said, 'I enjoy telling young adults. I share my experience and stress abstinence'.

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Table III. Frequency of disclosure to specific groups[a]

Who have you told you are HIV-positive?	Not applicable	None	Some	All
Bosses	93	159 (71.9)	47 (21.3)	15 (6.8)
Close friends	8	88 (35.6)	151 (61.1)	8 (3.2)
Casual friends	7	189 (61.1)	94 (30.4)	26 (8.4)
Parents	36	58 (20.8)	55 (19.9)	166 (59.5)
Brothers and sisters	20	69 (23.4)	45 (15.3)	181 (61.4)
Children	82	113 (48.3)	20 (8.5)	101 (43.2)
Other relatives	8	121 (39.3)	114 (37.0)	73 (23.7)
Health care providers	4	12 (3.9)	30 (9.6)	269 (86.5)
Sex partners	42	35 (13.0)	58 (21.6)	176 (65.4)

[a]Percents are presented in parentheses and are based on valid responses, excluding not applicable and any missing data.

Criteria for disclosure

Many participants have specific criteria for deciding to whom to disclose. These criteria were generally based on one of three factors: their relation to the person (health care provider, sexual partner or family member), the quality of their relationship (accepting versus rejecting) and the perceived ability of the other person to keep the information confidential. When discussing their relation to potential disclosees, 33 people mentioned that they only told those who 'need to know for medical reason, emergencies, etc'. For many of the women, health care providers, or at least those health care providers rendering direct care, represented a group that 'needed to know'. Women reported that they either 'Tell...people who do invasive procedures' or 'Tell...all health care providers'. One participant seemed to summarize a number of women's views by saying, 'When it comes to health care providers, I have to tell them'.

Women reported disclosing to family members and friends selectively. One participant said, 'Friends and family, I tell who I think can handle it'. Another participant said, 'Children will not know how to handle it if I told them. They know their sister died because she was very sick'. Another participant said, '[I]f they are ignorant or have anything to do with my child, I won't tell them'. Fears about how disclosure of their HIV infection would affect their child was an important consideration for many women who had children.

Some participants told people with whom they were living. One woman said, 'I knew I had to tell my boyfriend who I was living with'. Another respondent said, 'I've decided to tell my partner 'cause me and him live together and I don't want to keep it from him'.

Sexual partners were often told because of the risk of infection in sexual relations, 'You're only supposed to tell people who you're having sex with'. '[I] only tells sex partners, I do not tells other people'. However, other participants delayed or did not tell sexual partners. One participant said, 'This is my first relationship since my marriage—I intend to wait six months to tell him 'cause eventually he is going to insist on not using condoms...'. Another participant said, 'I feel like if I told the males, I wouldn't have sex anymore'. For these women potential negative consequences of disclosure represented criteria on which they made the decision to not disclose or to delay disclosure.

People who were perceived to be supportive and accepting were disclosed to selectively. 'I tell people who I know will be there for me no matter what. The people I have chosen has been there for me with other problems'. Another participant said, '[I tell] people who I need for help and support'. One participant said, 'Don't tell those few who I feel would blame or criticize me or it might embarrass my mother'. Nine participants specifically mentioned that they were concerned about confidentiality, 'I will tell a close friend as long as they will not tell anyone else'. One participant

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said, '[I tell] years after established relationships with them. Confidentiality is very important to me'. Clearly in these reports, women had personal criteria on which they based their decisions to disclose.

Some women described developing their criteria based on tests for attitudes, 'readiness' or rejection. Criteria that women looked for included people who were 'open minded' or who had neutral attitudes about people with HIV/AIDS: 'I feel them out first. I throw the subject [HIV/AIDS] out there and see what happens' and 'I determine how they feel about AIDS before telling anyone'. Participants generally described listening to someone to whom they were considering disclosing or 'Bring up the subject casually, and they will respond and that will tell you some things about them [and their likely response to disclosure]'. Another participant said, '...I'd ask them, ''What would you do if you were positive?'' and [disclose or not based on their responses]'. The end result of this process, as one respondent said, was to 'See how educated they are about HIV, and how they feel about people with HIV, and how they treat people. If these people act stupid about it, I don't share it with them'.

Emotional disclosure

Many participants based their decision to disclose their HIV infection on being close to someone, trusting someone or through prayer or feeling that it was the right person to tell. 'I decided to tell who I felt was close to my heart, but...I have to think about what to say and how to say it'. Another participant said, 'I choose only people that I'm close with. I feel comfortable with people who have confided something about themselves to me. I wouldn't tell a casual friend...I decided who was most important, and who I love, and who love me'.

Trust was specifically mentioned by 30 people, 'I tell people I trust who can keep a secret'. However, women acknowledged that trusting a person did not guarantee that the person to whom they disclosed would keep the secret. As a result of disclosure, some women reported that the people to whom they disclosed told others of their HIV status, '[I tell] who I feel will keep it confidential even though they've probably told someone [else]. There's no reason for me to tell. I'm through with telling!'. Another woman said, 'As for my family and friends, my mother told them'. Others decided, 'By praying. I meditate on it, and then I decide who I'll tell. Especially if it's a friend of mine and I know they care'.

Some women described a more intuitive basis on which they made disclosure decisions. One participant said, 'I feel the time is right. Something in my gut tells me it's time to tell other friends'. Other women described their decision as being based on intuition, how they felt at the moment or that they just 'blurted it out'. One woman said, 'It's hard. I just got tired of hiding it. I had to tell somebody. It was like having a gun to my head'.

Some women reported that after successfully disclosing to family members or partners they sought input concerning future decisions from that person. This input provided them with a level of emotional support in making these decisions. One woman said: '[I] talked with my husband and we decided who to tell'. A few women described their decision to disclose to family as 'natural' or easy, 'Yes, it is relatively easy deciding whom to tell. It is just how to tell them that is hard'. Such emotional support not only in making decisions about disclosure but in dealing with HIV infection was reported as important. Even so, disclosure remained difficult to most women. One woman, in discussing her conflict in disclosing to her mother, said: 'my stress level was so bad that I had to tell my mother, but it was one-and-a-half to two years later that I told her...'.

Demographic analysis of non-codable responses and disclosure categories

Initial analysis of demographic variables looked at differences between those who did not have a codable response ($n = 57$) and those who had a response that was coded into one of the three disclosure categories ($n = 265$) using the variables in Table I. Using χ^2 analysis for ordinal and Pearson's correlation for interval variables, only education was significantly different between these two groups ($r = 0.13$, $P = 0.022$) with those

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participants providing responses having a higher education level.

ANOVA, χ^2 and Pearson's correlation analyses were used to detect differences between disclosure category and participant characteristics. No significant differences between disclosure types were detected with the overall ANOVA test. The bivariate analysis revealed only one significant relationship. For those responses coded as 'emotional', 40.0% were from participants who resided in a rural area as opposed to the other two categories of responses (full disclosure and criteria disclosure) where 20.8% were from a rural area ($^2 = 5.673$, $P = 0.017$).

Overall ANOVA tests detected differences for seven of the variables where women reported responses to the question, 'Who have you told that you were HIV-infected?' (see Table III for response categories and sample sizes). Overall differences were detected for bosses, close friends, casual friends, parents, brothers, other relations and sex partners. No overall differences were detected for children or health care providers.

For those who were categorized as 'full' disclosers, 26.1% disclosed to 'all' their bosses compared to 4.4% of those in other categories ($\chi^2 = 16.3$, $P = 0.00$). Those categorized as full disclosers were also more likely to disclose to 'all' close and casual friends compared to those in other categories (45 versus 22% for close friends and 31.3 versus 5.7% for casual friends, $\chi^2 = 8.7$, $P = 0.01$ and $\chi^2 = 22.45$, $P = 0.00$, respectively). No significant differences were detected for full disclosers to parents, brothers and sisters, children, sex partners and health care providers.

For those categorized as 'criterion' disclosers, significant differences were detected for telling bosses, brothers and sisters, and other relations. Also, some small differences were detected for parents, children and sex partners but no differences were found for close and casual friends and health care providers. Those with a criterion were less likely to tell 'some' bosses that they were HIV-infected (15.2 versus 32.8%) and more likely to 'none' of their bosses (78.3 versus 60%, $\chi^2 = 7.9$, $P = 0.02$). Those categorized as using a criterion were less likely to tell 'all' of their brothers and sisters compared to those in other categories (55.4 versus 73.4%, $\chi^2 = 8.7$, $P = 0.01$) and other relations (15.6 versus 32.8%, $\chi^2 = 11.2$, $P = 0.00$). Some small differences were detected for 'criterion' disclosures who were less likely to tell 'all' parents, children and sexual partners that they were HIV-positive (respectively, 56.4 versus 69.2%, $\chi^2 = 5.322$, $P = 0.07$; 39.4 versus 45.4%, $\chi^2 = 5.59$, $P = 0.06$ and 61.9 versus 75%, $\chi^2 = 4.8$, $P = 0.09$).

For those designated as 'emotional' disclosers, significant differences were detected for only disclosing to bosses and children. Emotional disclosers were more likely to tell 'none' or 'all' of their bosses that they were HIV-infected compared to other categories of disclosers (71.0 versus 65.6% and 10.4 versus 1.2%, $\chi^2 = 8.7$, $P = 0.00$) and 'some' of their children (13.0 versus 1.5%, $\chi^2 = 7.7$, $P = 0.02$). No differences were detected for close or casual friends, parents, brothers/sisters, other relations, sexual partners and health care providers.

Discussion and conclusions

To our knowledge, the current study represents the first to explore how decisions concerning disclosure are made in a sample of predominately African-American women of reproductive age residing in the southern US. This sample was recruited through clinics, and may not be representative of women not currently receiving care and of a different demographic background. Additionally, approximately 56 women did not provide a codable response to the qualitative question asking how they make the decision whom to tell of their HIV infection. Because coding saturation was obtained in the 265 qualitative responses provided by the women in this study, further responses were unlikely to differ significantly from those reported here. Thus, generalizability of study results may be limited. However, the strength of this study is its focus on women at particular risk for sexual and vertical transmission of HIV, a particularly important group for health educators to address.

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Lazarus and Folkman's theory of stress and coping focuses on the importance of one's cognitive appraisal of an event and their reaction to it (Lazarus and Folkman, 1984). Cognitive appraisal is described as a key moderator between stress and effective mental health outcomes. The women in this study described disclosure processes that, for the vast majority, reflected hesitancies to disclose based on their appraisal of the negative consequences associated with disclosure. Such concerns were often described as the result of women's past experiences with stigma. Historically, most women have been infected through intravenous drug use or sexual contact with an intravenous drug user (Hanley and Lincoln, 1992). Most of these HIV-infected women are poor, single women of color who have young dependent children who may already be stigmatized for their race and economic status (Pizzi, 1992). Women have been viewed in the literature as vectors of HIV transmission rather than as individuals suffering a devastating illness (Kimberly *et al.*, 1995). Women may be more stigmatized than their male counterparts (Cline and McKenzie, 1996). The double standard of morality in our society prescribes more circumspect behavior of women than of men (Grove *et al.*, 1997).

Many women's descriptions of their decision processes reflected weighing benefits and costs of disclosure similar to that described in theories of reasoned actions (Fishbein and Middlestadt, 1994) as well as ways to apply criteria regarding the appropriateness or not of disclosure. However, many women discussed making decisions based on their emotional and intuitive processes as their sole criteria for disclosure more clearly reflected their personal appraisal of the negative consequences associated with disclosure than reasoned actions. These women were less likely to tell bosses and children of their HIV infection as compared to women providing other categories of responses. This may reflect more of a concern about how these two groups would react to this information. Past research supports that women's concern about stigma, rejection and violence related to disclosing their HIV-seropositive status are not unwarranted. Defeu *et al.* documented that negative reactions to disclosure are common, including betrayed confidence (50%), negative reactions from partners (30%) and abandonment (21%) (Defeu *et al.*, 1994). In a study by Zierler *et al.*, 45% of the adults who had experienced relationship violence reported that it was the result of their HIV infection (Zierler *et al.*, 2000). While the above-cited research documents women's concerns about negative responses such as rejection, abandonment and violence primarily within the context of women's relationships with husbands and sex partners, women may also fear similar negative consequences associated with disclosure to bosses and children.

Due to the fact that all women in this study were at risk for becoming pregnant and that 81% of the women had one or more children, the stakes for disclosure were especially high. For women with children, almost one-half had yet to disclose their status to any of their children. Additionally, every reference to children in the women's narratives dealt with trying to protect their children from any harm that disclosure of their mother's status could bring about. However, this protectiveness may very well erode the women's ability to effectively plan for the future of their children as their own health deteriorates.

A small group of women felt comfortable disclosing their HIV status to all and had markedly different appraisals of the consequences associated with disclosure as compared to women who had hesitancies. These women described a belief that in order to overcome societal stigma associated with HIV disease, it was important for others to be made aware that someone they know is HIV-infected. These women seemed unafraid of potential negative consequences of disclosing their HIV-seropositive status and a number of the women actively worked to increase awareness of HIV in their communities. This belief in the benefits of openness and/or confrontation of HIV-related stigma may have served as a resource for these women, reducing the fear of disclosure (Lazarus and Folkman, 1984). Women described as 'full' disclosers were much more likely to tell 'all' across

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categories, although significantly higher levels of disclosure were only found for bosses, and close and casual friends. Perhaps bosses and friends are more on the periphery of one's social network—this is where full disclosure would make the most differences. Because these women seem unafraid of being 'out' about their HIV infection, they may be the persons in the community whom people 'know' has the disease. Further studies need to look at the long-term impact that these women may make on the attitudes of community members and other persons with HIV infection. However, these women may, also, be the group most likely to suffer stigma and/or discrimination because of their disclosure.

Conversely, as has been documented elsewhere (Levy *et al.*, 1999), another small group of women had not disclosed to anyone, including sex partners, family, friends and health care professionals. This group of women had appraised the disclosure process to be too difficult or risky to undertake and engaged in avoidant behaviors to hide their illness. Clinically, avoidant behavior is associated with a host of negative outcomes including depression and anxiety (Folkman *et al.*, 1991). From a public health perspective, Kalichman and Nachimson found in their study of disclosure that men and women who did not disclose their HIV status to their sexual partners also did not practice safer sex, particularly condom use (Kalichman and Nachimson, 1999). Hence, the group of women in this study who did not disclose may be more likely to place partners at risk of HIV infection. This risk of infecting partners without notification takes on greater significance for women in this study, in that putting someone at risk of HIV infection through sexual activity without disclosure is a criminal act punishable by imprisonment in Georgia, North Carolina and South Carolina.

Because of the complexity and the on-going nature of HIV-infected women's struggle with disclosure issues, counseling support from health educators is critical to help women realistically appraise their concerns related to disclosure so that they can access needed support and services. Even though a majority of the women described the importance of disclosing in order to maximize life and health care options, many women continued to require support to successfully assess the potential consequences of disclosure and cope with the stress of the disclosure process. This may be particularly true for women who were identified as 'criterion' disclosers as they are less likely to disclose their HIV status to many family members and few bosses. These women may have a critical need for health education counseling in order to develop a plan for disclosing to and coping with reactions of people with negative attitudes about individuals with HIV infection.

Lazarus and Folkman's theory of stress and coping suggests that a better understanding of HIV-infected women's cognitive appraisals of HIV stigma, and the potential reactions of family, friends, sexual partners and health care providers, is a key to maximizing positive mental health outcomes and access to needed services (Lazarus and Folkman, 1984). Health professionals working with HIV-infected women need to be aware of the wide range of decision-making criteria that women use to decide how to disclose to a variety of people and routinely assess concerns about the disclosure processes. Health educators may be in a unique situation to intervene to assist women, especially women with children or at risk of having children, in understanding the importance of disclosure in making long-term plans for their children. By being aware of and sensitive to conceptual linkages proposed by stress theory, educators can more effectively counsel women in the benefits of disclosure to select groups as well as assist women develop plans for disclosing. Our findings underscore the need for counseling to be culturally and personally sensitive in order for disclosure to be as positive and successful experience as possible. Additionally, the health educator who understands cognitive processes is better prepared to respond effectively to a range of women's decisions in order to provide appropriate counseling to reduce unsafe and unhealthy behavior.

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