

EXPECTED VERSUS ACTUAL RESPONSES TO DISCLOSURE IN RELATIONSHIPS OF HIV-POSITIVE AFRICAN AMERICAN ADOLESCENT FEMALES

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Ten HIV-positive¹ African American adolescent females were interviewed regarding disclosure of their HIV infection in various relationships. Communication Boundary Management (Petronio, 1991) provided a framework for understanding disclosure patterns in these relationships. Participants described expected (n = 113) and actual (n = 94) responses to disclosing an HIV diagnosis. The findings indicate that expected response and the target of disclosure affect adolescents' disclosure decisions. Participants expected targets of disclosure to respond as follows: experience negative emotional reactions, provide support, treat them differently, tell others, or were unsure of a target's response. On the basis of these findings, five themes were identified related to actual responses to disclosure of HIV infection: different treatment, negative emotional reaction, received support, target told others, and treated no differently. Implications, limitations, and directions for future research are discussed.

Key Words: Adolescents, AIDS, boundary, disclosure, HIV, privacy, reactions

As the HIV/AIDS epidemic continues into the fourth decade, there is a need to focus not only on prevention, treatment, and education but also on maintenance of the lives of people living with HIV infection. People with HIV live, like most individuals, in a complex network of social and personal relationships (Greene, Derlega, & Frey, 2002). For every person with HIV/AIDS, family members and/or intimate others are in some way touched as well as countless other persons in the extended family, community, workplace, and school system. However, not all of these individuals are aware of the person's HIV status; hence, a crucial feature to examine in these relationships is disclosure, or how choices are made by a person to tell others about the infection (Greene, Derlega, Yep, & Petronio, in press). These HIV disclosure decisions are affected by, yet simultaneously affect, the relationships in which they occur. The present study was designed to further understanding of how members of one population, HIV-positive African American young women, manage their disclosure decisions in relationships.

People with HIV confront issues surrounding disclosure of this sensitive information. Controversy continues regarding the rights to privacy (non-disclosure) of HIV-positive individuals, compared with perceived public good (disclosure) of this sensitive information (cf. Bayer & Toomey, 1992; Lang, 1991). For example, Cline and McKenzie (2000) described the erosion of HIV patient confidentiality, where the balance has shifted from protecting privacy to protecting others and society. Greene, Parrott, and Serovich (1993) demonstrated how privacy attitudes affected perceptions of access to HIV information. This legal wrangling over the right to privacy versus the right to know has been contested in relation to issues such as names reporting, criminal transmission statutes (and their enforcement), and employment. At the center of these legal arenas are fundamental debates about interpersonal obligations to disclose.

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African American Adolescent Women's Health

African American women face many health challenges. They are, for example, disproportionately affected compared to Caucasian women in rates of breast cancer mortality, diabetes, and sickle cell anemia. Among these health challenges are HIV prevention and the maintenance of health and social support after HIV diagnosis. Black women are disproportionately affected by HIV and experience lower overall health when compared to White women (Leigh, 1995; McBarnette, 1996). Black women constitute the fastest growing population infected with HIV. AIDS was the leading cause of death for Black women in 1993, and the AIDS-related death rate for African American women is nine times as high as for Caucasian women (Centers for Disease Control [CDC], 1996, 1999). The pattern of HIV infection for Black women (predominantly reported heterosexual sex or injection drug use [IDU] risk factors) is different from that of men or non-Blacks. If the patterns of HIV infection are this markedly different, it follows that relational issues that affect HIV disclosure may be dissimilar by sex and race.

Contending with negative emotions related to HIV infection, such as shame and fear, in addition to health consequences, requires supportive communication; therefore women's ability to secure social support becomes vital to their well being. Studies of HIV related social support involve predominantly Caucasian gay male samples (see Song & Ingram, 2002), leaving critical cultural factors of African-American communities unexamined, for instance, the importance of informal and family social support (Green, 1993; Neighbors, 1985). African American family structures tend to include more extended family when compared to Whites (Taylor, Tucker, Chatters, & Jayakody, 1997). Family, which includes extended kin networks, are important influences in the use of health care systems for African American women (Shelton, Marconi, Pounds, & Scopetta, 1993). The extended kinship network provides benefits such as ability to care for sick and injured family members as well as promoting and maintaining emotional well-being in a wider societal context of racism and oppression (Nobles, 1997).

Structural elements, such as economics, also contribute to African American women's overall health, including their risk of HIV infection. As McBarnette (1996) explains, economics "is critically important in any discussion of the health status of African American women because it is derived from the notion of a stratification of people from lower to higher in terms of access to power, prestige, and property" (p. 43). African American women, compared with Caucasian women, are more likely to be single, live in poverty, and have less access to education. They are burdened with no or inadequate health coverage in addition to racism in and outside of the healthcare system (Leigh, 1995; McBarnette, 1996). Concomitant with these economic factors is the context of victimization, addiction, and social and cultural erosion present in these women's lives (Gasch & Fullilove, 1994). Disruptions in family life, drug use, violence, and lack of adequate housing represent many of these women's realities (Jones, 1989; Taylor, 2001). Amidst such a backdrop, the risk of HIV infection may not be a priority given other health and behavioral risks (McNair & Roberts, 1997). Parents with HIV are likely to be minority, poor and female (Leslie, Stein, & Rotheram-Borus, 2002; Schuster et al., 2000; Paige & Johnson, 1997), thus African American women may have the added stress of parenting and struggling with decisions to disclose to children (Schrimshaw & Siegel, 2002).

One specific group of African American females, adolescents, face additional challenges. In particular, African American adolescents contend with disproportionately high mortality and morbidity rates as well as health challenges such as pregnancy, parenting, violence, substance use and involvement with the criminal justice system (Cohall & Bannister, 2001; Jones, 1989; Staggers, 1989). In some ways, African American adolescent girls face the struggles common to all adolescents (e.g., identity development and separation, egocentrism and exploratory risk taking). Normal developmental tasks of adolescence, such as onset of puberty and changes in cognitive development, are important in understanding health related behavior (Greene, Krcmar, Walters, Rubin, & Hale, 2000). To compound these developmental stages, however, life and environmental circumstances present unique challenges for African American adolescents (Jones, 1989).

Social and cultural factors contribute to the prevalence and risk of HIV infection for African American female adolescents. There is a greater prevalence of STDs among some of their sexual partners, African American adolescent boys and men, and relationship dynamics may make it especially difficult to negotiate safer sex (Crosby, DiClemente, Wingood, & Sionean, 2000). For instance, differing gender roles and power imbalances between women and men exist in the African American community (Kline, Kline, & Oken, 1992; Miller, Burns, & Rothspan, 1995; Weeks, Grier, Radda, & McKinley, 1999). Lower income Black women and girls report that traditional sexual roles granting men more sexual freedom still exist in the Black community (Fullilove, Fullilove, Haynes, & Gross, 1990). Crosby et al. (2000) found that African American adolescent females with steady sexual partners who believed in male control in relationships tended to report more frequent unprotected vaginal sex. For many young adults, the desire to be in a romantic relationship can outweigh the need for preventive sexual behaviors (Kellar-Guenther, 1999).

Women, HIV/AIDS and Disclosure

Women infected with HIV must contend with numerous issues, such as depression and stress (Kaplan, Marks, & Mertens, 1997), health, childcare, maintaining and initiating relationships, securing social support, and economics. Among such challenges, obtaining support and the decision to disclose one's HIV status place women at risk for ostracism and isolation. However, the disclosure of HIV infection can decrease stress and allow a person to obtain needed support from others. Disclosure generally has positive health consequences (Derlega, Metts, Petronio, & Margulis, 1993; Pennebaker, Colder, & Sharp, 1990; Remien, Rabkin, Williams, & Katoff, 1992).

Although disclosure can be beneficial, there also exist potential costs; the stigma associated with HIV/AIDS is well documented (e.g., Crawford, 1996; Leary & Schreindorfer, 1998). As much as failure to disclose can result in untapped social support, it is also possible to lose social support through disclosure (Greene et al., in press; Hays, Turner, & Coates, 1992). These disclosure decisions are often stressful and difficult for HIV-positive persons (Greene & Serovich, 1996; Holt et al., 1998; Marks et al., 1992), and hence these individuals disclose selectively. It is common to argue over disclosure decisions, particularly decisions to disclose to friends and/or extended family (Stulberg & Buckingham, 1988).

One problem with many of the HIV disclosure studies is the use of exclusively male samples (e.g., Hays et al., 1992; Marks et al., 1992; Norman, Kennedy, & Parish, 1998; Perry, Ryan, Fogel, Fishman, & Jacobsberg, 1990). With few exceptions (e.g., Kimberly, Serovich, & Greene, 1995; Serovich, Kimberly, & Greene, 1998; Simoni et

al., 1995; Wolitski, Reitmeijer, Goldbaum, & Wilson, 1998), there is scant research on women's HIV-disclosure patterns. What research does exist shows some differences between women and men; for instance, Kimberly et al. (1995) found that in the disclosure of HIV process for women, there was an initial stage (often 6 months) where they told no one, and this is different from findings reported for men. Several studies include a small portion of women but data are not reported separately (e.g., Derlega, Sherbourne, & Lewis, 1998; Derlega, Winstead, & Folk-Baron, 2000; Greene & Serovich, 1996), for an exception see Derlega et al. (2002). Meta-analytic evidence indicates it would be important to examine disclosure patterns separately for women and men (Dindia & Allen, 1992; Dindia, 2002). Thus, we need more information on women's disclosure of HIV.

Recent research has provided more information about HIV disclosure decisions, but there is a need to better understand the disclosure process. Communication Boundary Management theory (CBM) offers one useful perspective for understanding the decision to disclose one's HIV status (Greene et al., in press; Yep, 2000).

Communication Boundary Management Theory

CBM is a systems approach to decision making about disclosure that focuses on boundary regulation (cf. Derlega & Chaikin, 1977). Systems theory, in this sense, describes how information is shared between and among individuals, families, or organizations and their environment by focusing on the structure or boundaries that separate systems. The function of these boundaries "is to protect the differentiation of the system" (Minuchin, 1975, p. 53). CBM specifically addresses how people balance the need to make public disclosures with the need for privacy given that disclosure to others involves risks (Petronio, 1991, 2000, 2002). The revelation of personal information (e.g., HIV status) involves risk because individuals make themselves potentially vulnerable disclosing such information. Revealing information also places a recipient in the position of sharing "in the responsibility of information that may start as personally private" (Petronio, 2000, p. 38). For instance, when a woman decides to risk telling others her HIV status, the recipients share responsibility for subsequent disclosure (or protecting the information). Cleveland, Walters, Skeen, and Robinson (1988), for example, reported that 47% of parents of homosexuals would not want anyone outside of the family to know of their child's AIDS diagnosis, and 16% would not even want the diagnosis shared with other family members.

One of the strengths of CBM is that it is transactional, focusing, in part, on why people make decisions to disclose by incorporating relationship factors. It is not always true that people disclose many things as a relationship deepens as some relational theories, such as Social Penetration Theory (Altman & Taylor, 1973) would indicate. Indeed, Roloff and Ifert (2000) argue avoiding disclosure (or non-disclosure) can be a functional conflict management strategy in relationships. Perhaps HIV-positive people do not want to spend all their time/energy discussing the issue or want to avoid creating distress for others. CBM is helpful in understanding how individuals manage disclosure decisions.

To manage the disclosure and receipt of personal information, individuals raise and regulate boundaries as a form of protection and a way to decrease the possibility of losing face (Petronio, 1991, 2002). People make decisions about whether to share personal information on the basis of boundary structures and a rule-based management system (Petronio, 1991, 2000). Because individuals believe they own private information (e.g., salary information, HIV status) they raise borders to help them

protect this information. Individuals generally believe that they possess exclusive ownership rights to their private information, and HIV status is primarily viewed as private information (Greene et al., 1993). Boundaries are established through the control of information, what access is granted or denied to others. This access represents how permeable or impermeable an individual makes boundaries. If a person possesses impermeable boundaries, "access to information about the person is limited, autonomy is achieved, and vulnerability is at a minimum" (Petronio, 1991, p. 314). When boundaries are permeable, individuals allow others access; when boundaries are impermeable others are not granted access. Partners also coordinate their individual boundaries to establish a balance between personal autonomy and relational intimacy.

The rules that individuals create regarding boundary access are affected by things such as culture and motivation. Cultures have different privacy values that influence people's decisions about boundary access and closedness as well as their individual motivations for disclosure (Petronio, 2000). Individuals disclose information for a variety of reasons such as feelings of obligation (e.g., to family), to secure emotional support, and to alleviate loneliness (cf. Derlega et al., 2002; Derlega et al., 2000). Individual motivations for disclosure and how these are carried through are still questions that remain to be answered, but we do know that relational partners must coordinate the sharing and regulation of these boundaries because information is co-owned as described above. This suggests that timing of disclosures may be important for individual's to have their needs met and to accomplish their relational goals.

Women may consider three relevant factors when conveying or concealing their HIV status (Petronio, 1991): expectations about the recipient's response, selection of message strategies, and content of the message. Expectations about disclosing HIV status differ depending on relationship type and intimacy levels (Yep, 2000), characteristics associated with perceptions of the potential disclosee. In this sense, disclosure is strategic. Indeed, Greene and Serovich (1995) using CBM to explore disclosure of HIV, reported relational quality and anticipated response were the best predictors of willingness to disclose information about HIV.

Past research indicates that individuals often feel that immediate family should be the target of HIV disclosure more than extended family and community members (Greene & Serovich, 1996; Serovich & Greene, 1993). Researchers have, thus, established that the target or recipient explains some disclosure decisions of HIV-positive persons (e.g., Derlega, Lovejoy, & Winstead, 1998; Mansergh, Marks, & Simoni, 1995; Serovich & Greene, 1993; Simoni et al., 1995). For example, reports of HIV-status disclosure to partners, parents, siblings, and friends are different. There is, thus, variability in who is told about the HIV diagnosis (Derlega & Winstead, 2001). Based on the preceding research, the following research question (RQ) was advanced:

RQ1: What role does the target play in HIV-positive African American adolescent women's disclosure decisions?

Expected response is another crucial factor in individual's decisions to disclose HIV status. If an HIV-positive person anticipates a recipient to respond negatively or is unsure of the target's response, he/she will likely not disclose that information (Serovich et al., 1998). In contrast, if the expected response is positive or supportive, the person will likely disclose it. Kimberly et al. (1995), for instance, discovered that

women specifically stated that expected response affected their decision to disclose their HIV infection. Unfortunately, few studies of reactions to disclosure of HIV diagnosis (either expected or actual reactions) exist. Simoni et al. (1995) and Mansergh et al. (1995) constructed three response categories of family reactions (provided emotional support, became angry, or withdrew) and asked two samples to place the response of each person who knew of HIV infection into one of the categories. They found differences by target. Serovich et al. (1998) inductively identified six general themes (and 31 categories) women reported as responses to disclosure of HIV infection: emotional, intellectual, physical, spiritual, relational, and instrumental. Serovich et al.'s study is limited because it does not consider both expected and actual reactions, has a predominantly Caucasian sample, and the categories lack parsimony. More work, therefore, is needed to understand the role of expected response in women's disclosure decisions. Therefore, the following research questions were posed:

- RQ2: How does expected response affect HIV-positive African American adolescent women's disclosure decisions?
RQ3: How do expected response and actual response to disclosure of an HIV diagnosis differ?

Summary. The findings from the extant literature generally indicate that people disclose their HIV infection to individuals closer to them emotionally and physically. It is uncertain, however, if this result applies to women because the majority of the research has been conducted with men. Potential differences in disclosure decisions may be complicated by possible child care issues, stigma stemming from lack of visibility in the epidemic, and African Americans with broader family/kin networks (see Rose, 1998). The literature reviewed indicates that anticipated response, goal, and targets are important factors in disclosure decisions. The present study explores these factors in descriptions elicited during interviews with HIV-positive African American adolescent women.

METHOD

Participants and Procedure

Ten African American adolescent females with HIV age 15 to 19 were interviewed regarding disclosure of their HIV diagnosis in various relationships. All participants reported infection through heterosexual contact with older men (average 11-year age difference). Half of the participants had children (range 1-3), and they reported 3-7 people living with them at home. Time since participants had been diagnosed HIV-positive ranged from 1 month to 2 years 11 months; CD4 counts ranged from 20 to 780 ($M = 320$) and viral loads from 540 to 492,818 at the time of the interviews.² Three women were not on HIV related medication, two women were taking AZT, and five women were taking AZT combined with other medication.³

Participants were recruited through the Pediatric Department at a regional medical center. The hospital is located in a midsized community in the southeast and serves a number of smaller surrounding communities. All participants who met the study criteria (HIV+, African American, and age 14-20) were contacted by the Pediatric Department's social worker, and 10 (80%) agreed to participate. The sample was relatively homogenous in terms of age, gender, race and SES, however, the focus of the

present investigation was to elucidate descriptions of disclosure process decisions. Participants were given a \$10 phone card on completion of the interview.

Consent was obtained from participants prior to participation but not from parents, regardless of age. The emancipated minor status of most participants and the lack of parental knowledge of several participants' HIV status warranted this procedure and was approved by the human subjects committee. Those who agreed to participate were notified that the study would be tape recorded with all personally identifying information deleted from transcripts (including reference to names and places). Participants selected what location would be most comfortable for the interview as Morse and Field (1995) suggest; most (seven) were interviewed in their homes (two in a private office at the hospital and one in a back room of a restaurant).

Interview Procedure

A social worker with previously established relationships with the participants as clients interviewed all of them. The interviewer was trained prior to conducting the interviews; training included several practice interviews and detailed analysis of the practice interviews with the first author. The interview procedure included identifying members of the participant's social network and identifying, for each network member, variables related to disclosure of HIV (e.g., knowledge of HIV status as well as expected and actual reaction). The interviews were tape recorded and lasted from 30 to 90 minutes; audiotapes were transcribed verbatim and verified by at least 3 trained research assistants and the first author. We were reaching saturation by the 7th interview with the significant repetition of information and no new information or themes occurring (Leininger, 1994).

On the basis of previous research (e.g., Greene & Serovich, 1996; Petronio & Kovach, 1997; Petronio, Reeder, Hecht, & Ros-Mendoza, 1996), the interview protocol operationalized components of Communication Boundary Management theory. The interview began by asking a participant who she considered to be family and friends, or to identify her social network. Basic information (e.g., age, sex, and relational quality) was collected for each person mentioned. Next, the interviewer facilitated descriptions of disclosure/nondisclosure about HIV decisions for each person mentioned (and any others mentioned). Information specific to disclosure patterns was also collected; for each target person, information was collected about HIV-status disclosure (yes, no, in future, or via third party), expected and actual response to disclosure (if it had occurred), when told/when might tell, why told/not told, setting for disclosure (where), and content of disclosure message (e.g., "What exactly did you say?"). Finally, information about the participant's medical history was obtained from hospital records (e.g., number of infections, hospitalizations, CD4 count, and medication regimen); consent for access to records was established before interviews began.

The interview transcripts were content analyzed for the topics described above (Morse & Field, 1995). Three graduate students coded data; independently, each student coded transcripts with individually identifying information deleted for CBM variables described. Then, the coders and the first author developed sub-categories or themes related to each of the topics (e.g., different treatment was a theme under actual response to disclosure) and looked for relationships between the themes as well as between the themes and topic categories. Initial reliabilities for number of people disclosed to and not disclosed to were very good: kappa = .94 and .96, and reliabilities for expected versus actual response categories were also good: kappa = .89 and .91.

TABLE 1
DISCLOSURE OF HIV DIAGNOSIS BY PARTICIPANT

Partic.*	Disclosure # Told	Nondisclosure # Not Told	Future # Will Tell	Indirect #3 rd person	Targets/ Total	CD4	Time since dx**
01	12 (46%)	0 (00%)	5 (19%)	9 (35%)	26	170	15
02	4 (25%)	5 (31%)	0 (00%)	7 (44%)	16	400	8
03	4 (25%)	7 (44%)	2 (13%)	3 (19%)	16	290	1
04	6 (25%)	1 (04%)	2 (08%)	15 (63%)	24	20	14
05	1 (07%)	12 (86%)	1 (07%)	0 (00%)	14	320	8
06	2 (13%)	14 (88%)	0 (00%)	0 (00%)	16	370	21
07	5 (29%)	8 (47%)	2 (12%)	2 (12%)	17	430	11
08	7 (44%)	0 (00%)	1 (06%)	8 (50%)	16	280	1
09	1 (06%)	8 (44%)	9 (50%)	0 (00%)	18	690	35
10	4 (21%)	7 (37%)	5 (26%)	3 (16%)	19	230	21
×	4.6	6.2	2.7	4.7	18.2	320	13.5

* Participant

** Time since HIV diagnosis, measured in months

After establishing reliability reported above, disagreements on any variable were discussed with all coders and one author until 100% agreement was reached.

RESULTS

Units of analysis for this project were the participants' descriptions of disclosure and descriptions of actual and expected responses to disclosure. There were 148 disclosure targets (identified as social network members) potentially available from the interviews. For expected response, we recorded 113 descriptions for use (ranging from several words to multiple pages); the six categories for expected response captured 94% of the data. For actual response, we recorded 94 descriptions for use (ranging from several words to one and a half pages); the five categories for actual response captured 93% of the data. Note the lower actual response totals because some targets were not selected for disclosure (i.e., had no actual response); however, data were obtained for expected response for these targets.

There were patterns concerning which members of participants' support networks were told about the HIV infection (see Table 1). Individual differences seem apparent in disclosure of HIV infection. In addition, there were indications that other progressive patterns for who was told (and in what order) existed in relationships. Differences by target of disclosure are summarized in Table 2. There were differences; for example, more mothers than fathers were told about the HIV diagnosis. Additionally, most boyfriends were told, although ex-boyfriends were not necessarily told. There was more variability in disclosure patterns to siblings and aunts/uncles.

Order of disclosure. For each participant, we created a timeline of the disclosure process (including potential for when a person might be told) for each target person. Mothers were told on the first day participants knew of the infection in 8 of 10 cases. Thus, for African American teenage girls, mothers are significant figures in this health context. Others told on the first day sometimes accompanied the participant to obtain test results and included friends (most often after mother), sister (one), boyfriend's mother (one), cousin (one), grandmother (one), and father (one). Three participants told their boyfriends on the first day, although some waited up to a month to reveal the diagnosis to their boyfriend. Ex-boyfriends were told later, often after a period of

TABLE 2
DISCLOSURE OF HIV DIAGNOSIS BY TARGET

Target	# Told/Knows	# Will Tell	# Will Not Tell
Boyfriend	7	1	0
Ex-boyfriend	4	2	2
Mother	8	1	1
Father	3	1	4
Sister(s)	6	3	4
Brother(s)	8	4	7
Grandmother(s)	4*	2	5
Grandfather(s)	1**	1	4
Aunt(s)	10*	1	8
Uncle(s)	2**	0	5
Cousin(s)	9*	2	9
Children	0	2	0
Best Friend	4	0	0
Friend	12	5	8
In-laws	11**	0	5

* occurred primarily via indirect disclosure (third party)

** occurred *exclusively* via indirect disclosure (third party)

weeks, a month or a year. In two cases, participants reported that they intended to tell the ex-boyfriend but had not. Participants tended to either tell no one or tell a few people initially and then wait several weeks to disclose further. When asked about when they might tell a specific person, responses often included when they became sick and showed symptoms of AIDS, or when they saw a person if that person lived some distance away. Participants did, however, specifically refer to symptoms in some disclosure decisions; for example, one woman stated she would tell her brother “when I get sick and can’t get out of bed” (06). There was contradictory evidence of the relation between disclosure with time diagnosed and disease progression (also see Table 1). For CD4 count (recall lower score indicates more disease progression), the correlation with number told ($r = -.58, p = .07$) was stronger than for number will tell ($r = .37, p = .29$). The correlation for time since diagnosis indicated a stronger relation with number will tell ($r = .73, p = .02$) than number told ($r = -.30, p = .41$). Thus, participants who were more ill were more likely to have disclosed their diagnosis to more others, but how long they had known their diagnosis only predicted the likelihood of disclosing in the future (not the number disclosed to).

Expected Response to Disclosure

We identified six themes as expected responses to disclosure of HIV infection (RQ2): expectations of negative emotional reactions, receiving support, being treated differently, targets telling others, being treated no differently, and being unsure of a target’s response. These six expected reactions were crucial in decisions to disclose HIV infection. As a result of anticipating negative reactions, participants often chose not to reveal their status; conversely, some instances where more positive reactions were expected resulted in disclosure.

Negative emotional reaction. The most common theme was the expectation of a negative reaction, such as anger or shock, from others at the disclosure of their HIV status. Some participants reported that the other person would not believe they were HIV-positive, while others expected the recipient to be “mad” or “upset.” As one

adolescent said, "I felt like she [mom] was going to be mad" (01). Another participant explained how she expected her boyfriend to react, "I told him there was something I needed to talk to him about. I expected him to go off, and you know" (09). Another participant (05) stated, "I wouldn't tell that boy for nothing, man, when he gets mad he say little stuff, you know. And he's always making trouble, always saying little stuff." Some women expected their friends to respond poorly, as was the case with a woman who felt her friend would react "very badly, like he can't touch me" (10). Another participant (07) felt that her friend might react poorly, although she believed she would tell him soon:

I had thought about it, but then I was scared that it might mess our friendship up. I don't know why I did, but I just did. So, I don't know when I'm gonna; I think I might eventually tell him, too; sooner, I think.

Some participants expected an extreme negative reaction of violence by members of their family, particularly male family members, to the supposed source of infection (past/current boyfriend). One woman felt her brother was "gonna go crazy and want to kill somebody" (07). Another participant (05) thought her brother would be angry and violent, and, thus, she remained silent. As she explained, "He would be mad, at ME! Because he [the ex-boyfriend] was too old for me in the beginning. So he'd be real mad I think . . . I ain't told him 'cause he gonna kill [her boyfriend]."

Expected to be treated differently. Women had general ideas that others might not respond well if told about the HIV diagnosis. In particular, they were aware of the potential consequences of stigma attached to HIV and expected some people to treat them differently after learning of the diagnosis. These expectations were generally vague and less detailed, but they centered on being treated differently in a negative way. For instance,

Probably I would tell somebody about it, except now I won't, you know, 'cause I know somebody whose got it and nobody wants him around them . . . I wouldn't take it like he, he laughs it off or whatever, you know. He's like "Ya'll are crazy." But me, I wouldn't do that. I wouldn't do that, I'd probably get all upset.

Women were especially afraid that others would "act weird" or "scared," after the disclosure. As one woman said, "I don't know if I would tell her 'cause she might try to act funny" (06). Numerous participants reported that they expected to be treated differently (always negative) after disclosing their HIV status. One participant summarized these concerns, " 'Cause people, a lot of people, don't know how to deal with it anyway. They think it, you know, by touching you or stuff, they don't know the stuff" (03). Another participant felt one of her brothers would "act like it is contagious and isolate her and not understand" (07). Another thought her mother would "act scared of me. I think she [would] take it pretty hard, but I can't be sure" (09). Others expected that they would see the person much less. Participants also reported expecting significant relationship redefinition, such as "stop being friends." One said, "I thought she [her friend] would just like leave me alone, you know, stop talking to me" (04). Some women feared increased isolation from everyone; for instance, one said, "I thought they were going to run away from me and not come back" (08).

Expected to receive support. Few participants expected people to be very supportive when told about the infection, but some women did expect to receive support, ranging from "being there" to childcare. One woman expressed the concern that "somebody's

gonna have to take my kids, and I want them cared for right" (08). Another (02) felt that telling an aunt would help her, and one participant revealed that she expected support in the form of transportation: "I needed to get around to the doctor" (07). Finally, one woman said about her friend, "she [would] be there for me."

Expected targets would tell others. Another rare response by some participants was the expectation that others they disclosed to would reveal the information, even if specifically asked not to do so. One woman said, "But everybody else, it's just that, I know if I tell one of them, eventually they were going to run off at the mouth and tell somebody" (03). Some women felt that aunts, grandmothers, and other family members would talk among themselves; for instance, one participant shared, "I wouldn't tell her [aunt]. Oh, her and my grandma talk. They'd get on the phone too much" (05).

Expected to be treated no differently. A very small portion of participants expected no differences in their relationships or treatment by others as a result of disclosing HIV infection. One woman reported that she thought her parents would "take it in stride" (06). These participants were confident of potential targets' reactions, especially if they knew the target had experience with people living with HIV and/or AIDS. As one said, "She [friend] told me her brother had AIDS, so I didn't think there was going to be a big reaction" (01).

Unsure what response to expect. The last expected response identified in the interviews was uncertainty concerning how others would respond to their HIV disclosure, that is, whether they would be supportive, react badly, and so on. As one said, "Well, I was always wondering if they were going to, you know, treat me different[ly] or treat me the same way they [had] been treating me. I don't know, stuff like that doesn't bother me" (02). Another expressed her ambivalence about telling a friend due to the uncertainty of his reaction: "Now, he'd be about the only one I'd be afraid to tell, 'cause I don't think he, well, then again, knowing him, he wouldn't turn against me. But I just feel like he might would change our friendship" (03). Participants unsure of others' reactions worried about the effect disclosure would have on their relationships, particularly if the relationship was strained. As one (09) said,

Um, I guess 'cause we don't really get along that good, but I don't think she, she really is the type that [would] pull away because she knew the same guy that I knew [HIV-positive]. And she, you know, she didn't never talk down to him, so [I] might or might not tell her.

Actual Response to Disclosure

We identified five themes that related to actual responses to disclosure of HIV infection (RQ3): different treatment, negative emotional reaction, received support, target told others, and treated no differently.

Different treatment. Many participants experienced a difference in treatment from others, including health care personnel and mothers, once they disclosed their HIV status. For example,

Once I went to the hospital and this Black lady, this nurse, she treated me bad. She said, "You know, you have to wear gloves. Let me get two pair of gloves 'cause I wouldn't want to stick myself with your blood" (02).

Participant 10's mother seemed concerned about casual contact with her daughter after learning the diagnosis:

Last night I picked up a french fry out of the thing, and she had some ketchup under it. I stuck my french fry in the ketchup, and she thought I had bit off it. She started running off at the mouth and stuff like that, and I told her I hadn't bit off of it. . . . If I just pick it up with my hands, she almost don't want to eat it anymore.

Another woman (05) revealed that she and her mother experienced a turbulent relationship, unlike the relationship with her father, leaving her confused about the status of things:

My dad, we had a close relationship. I think we got closer, but my mom, I don't even know, we just up and down. We were up and down before, but I don't know if we're more up or more down now, seems like more down, her always on me about the HIV.

Negative emotional reaction. The second most frequent anticipated response was negative emotional reactions, and many participants actually experienced them. Participants identified people in their lives with whom they did not currently (or in the future) want to share their HIV status, due to possible negative reactions. Some of the reported negative emotional reactions to actual disclosure occurred only initially, whereas others were more long lasting.

Participants reported that the recipient of the information was often "shocked" or "cried." One woman relayed her aunt's reaction to the revelation, "She cried, and I never seen her cry before that" (04). Other women discussed how their mothers were mad, upset, and began crying at the news. Shock seemed to be a common reaction, as one woman explained: "Well, at first she didn't believe me, she didn't believe me, 'cause she thought I was joking. She was just shocked, you know, like she wouldn't accept it" (02). A participant discussed how her mother was not angry, but her reaction was:

more like shock. Not, you know, she didn't cry, she didn't holler or scream or cuss me out. She was just like in shock . . . I gave her the pamphlet and I was crying and she just read it and she was like "What, for real? Are you serious?" You know, that kind of shock (03).

The shock often took the form of disbelief. As one person said about her sister, "She thought I was lying. She thought I was playing" (03). This participant's father also wished to find support:

He was shocked or whatever. He ain't go to work all week, he would walk around crying and all that stuff. Now, he wants to go to somebody, he want to have somebody to talk to. He don't want to tell them what I got, but he just gonna tell them I got cancer (06).

There were several instances reported where a family member reacted violently toward the assumed source of infection. For example, participant (08) stated that her brother "wanted to find the boy, ran outside to find him to beat him up." Her uncle indeed "beat the boy up real bad." Her friend also reacted violently:

And she asked me what was wrong, and I took her upstairs and we sat down and started talking and then I told her I had, um, HIV. She [mistakenly] thought [current boyfriend] gave it to me. She was going to go downstairs and cut him (08).

One reaction not expected by participants was topic avoidance by the targets of disclosure (i.e., refusing to discuss HIV/AIDS). This occurred primarily with relational partners. As participant 04 said about her boyfriend, "He won't talk about it, and he'll walk away and walk outside or something. He just doesn't want to deal with it right now." Most of this type of response occurred with men, as one said, "He just didn't say much, it was like he wouldn't talk to me at all" (09). Another adolescent described this

avoidance, "It's like he, he ignores it. He's never been the type to talk out things, like he keeps all his inside" (10). Some parents also ignored the topic. As participant (10) said, "They [parents] just change the subject or walk out," yet 02 claimed "Well, we [mom and she] talk, but we don't talk about it."

An additional unanticipated negative emotional reaction was the perception by many HIV-disclosure recipients that they should have been told earlier. This was especially the case for family members, who saw the delay in sharing information as a form of relational violation. Participant 01 described her grandmother's response as "She wants to know why she was the last person to know, then talk about 'I bet all your friends know, I betcha [name] know. I'm your grandma, why you ain't tell me?'" One woman (07) disclosed her status in a letter to her father: "He just wants to know why he was the last person that knew, and why my mother didn't tell him." Other participants described how family members were angry about the delayed news:

She [aunt] was mad because I, she, we were always close. She felt like I should have told her . . . She was like much as we been through and because I used to stay with her when I was little. She was like, "Why didn't you tell me?" Then she was mad with my momma for my momma not tell her, too (04).

Thus, women received the expected negative reactions in addition to two unexpected negative emotional reactions, topic avoidance and perceived relational violations.

Received support. According to participants, some people were very supportive when told about the infection; women received both instrumental and expressive support, indeed more than they expected. Participants were much more specific about the tangible support received compared with emotional support, such as the adolescent who described how her cousin hugged her right away and "bought me medicine" (04). This same participant also reported receiving instrumental support from her mother: "She was, like, way supportive. She was like 'Wait, you need to read about it since you feel like, think you contagious and stuff.' She got stuff for me to read and stuff." She also shared that a friend would "make sure I take my pills, everyday she calls. 'You taking your medicine? Go get your medicine and stuff.'" In addition to reminders about medication, friends drove adolescents to appointments.

Several participants mentioned the importance of physical contact (e.g., hugs) immediately after disclosure, and some said they received helpful emotional support. Such support ranged from listening to promises of "being there" (07). Participant 01 reported that her best friend made herself available:

She was like, she told me if I ever needed to talk, like I could call her up. 'Cause we had talked about it before when I first went and got tested, and we had talked about it, if what was my result. We had talked about that.

An ex-partner told one woman, "Well if you need anything, just let me know, and I'll be there" (08). Many participants received reassurance that things would be "all right" from cousins, mothers, and friends, and that nothing would change in their relationships (additional research would be fruitful to see if indeed nothing changed in these relationships as promised). As one woman said about her friend, "She was like, it doesn't change anything" (07). Another said about her mother,

I told her that I had went to the doctor, and they did some blood work and they found that I was HIV-positive and it was found in my blood and, and, you know, stuff like that. Um, she after, um, after like she asked me if I was all right, cause I was like crying and crying and stuff and she tell me not to cry and everything gonna be all right and stuff (02).

Participant 08's best friend offered support, as well as a reassurance that their relationship was safe: "Well, she said whatever I need just let her know, she my friend and we'll be friends 'til the end. And I said, okay."

Target told others. Women in this study revealed that some people they disclosed to did indeed tell others, even when specifically asked not to. Participant 04's brother told everyone without asking her:

I felt like it was my place to tell everybody, my family. It was not his place to go out and tell, you know. Go out in the street and, I mean, some people he told didn't even know me. It bothered me for a while, it hurt for a while, you know, I was scared.

She continued by stating that she no longer talked to him because of his indiscretion:

I don't talk to him. He calls every day, I hang up. My momma says I should forgive him, like I should forgive him. And I thought what he did was wrong. I would have expected it from a stranger, you know, somebody else.

Most women expressed surprise, anger, or hurt at the discovery that others were telling about their status. As participant 07 said, "I can't believe she did that, went and told all of them." This third-party disclosure was not uncommon, although its occurrence was mixed between requested and not. A few women wanted another (often mother or sister) to tell others because they thought it might be emotionally easier, they did not know how to tell others, or they felt too busy to find the time.

Treated no differently. Some participants reported no changes in a relationship or treatment as a result of disclosing their infection. As 01 said, "We be tight as ever," and 08 concurred, "It's just like things are like they always was, they all act the same." One woman's sister did not change her treatment of her: "It took me a while to finally tell her, 'cause usually I keep my nieces every summer—I thought she was gonna stop letting them come home but she didn't. She said I was her sister" (04). This same participant explained that only her brother treated her differently: "The only person that really, you know, that, um, did wrong was my brother. Everybody else was like, 'it doesn't change anything, why didn't you tell us sooner'? and stuff like that" (04). Participant 01 relayed that friends did not alter their behavior, "She was the same. I still talk to her. She was saying, 'I'll still be your friend and you can still keep my daughter or whatever.'" Another woman, (02) reiterated this support by friends, "They all don't, they don't treat me differently than they treat[ed] me before. [name] said the point that we all grown up now, and we need to stick together and stuff like that."

Summary. Research questions 2 and 3 explored anticipated and actual responses to HIV disclosure. For expected response, the data were captured by 6 categories, for anticipated response there were 5 categories. The order of the frequency of particular expected responses and actual responses were not identical. For expected response, negative emotional reactions were the most common (similar to Serovich et al., 1998). For actual response, however, different treatment was the most common response.

DISCUSSION

As this study shows, there is variability in HIV disclosure patterns revealing the complexity of disclosure choices for HIV-positive adolescent females. Some women told almost no one, whereas others disclosed to the majority of their social network.

For all of them, however, the expected reaction of others affected disclosure decisions. Disclosure decisions are made selectively, people do not always "tell all" in relation to HIV diagnoses (see Greene et al., in press). Dindia (2000) recently noted, "There is an inherent bias in the self-disclosure literature that self-disclosure is good . . . In general, self-disclosure theorists and researchers do not discuss the negative ramifications of intimate self-disclosure, the personal and relational risks" (p. 34). She points to a need for more theoretical essays and empirical research, a void this study can fill as it examines how people balance risks in opening boundaries through disclosure. Petronio's (1991, 2000, 2002) Communication Boundary Management theory served as a useful tool for examining the disclosure process. CBM has been applied to a limited extent to disclosure of HIV infection (e.g., Greene, 2000; Greene et al., in press; Greene & Serovich, 1996; Yep, 2000). The present study indicates CBM can be applied to understand and provide clarity about African American women's HIV disclosure decision rules in terms of constructs such as ownership, rule construction and violation, and timing.

Women delineated clear disclosure rules based on their *expectations* of others' reactions and their perceptions of others' *actual reactions* to disclosure. Most women anticipated negative reactions to the disclosure of their HIV infection, such as different treatment (e.g., others not wanting to touch them), negative emotional reactions (e.g., anger and violence), and a recipient target telling others. For example, women did not disclose their infection to those they feared would not keep the information private; this fear of further disclosure reflects a sense of ownership of the HIV diagnosis information. Women felt that their HIV diagnosis was their private information, as CBM explains. When a negative reaction was expected, participants often displayed impermeable boundaries by not disclosing regarding their condition (cf. CBM); when more positive reactions were expected, they often possessed more permeable boundaries through disclosure. This finding supports research by Serovich et al. (1998) that argued for the importance of expected reactions in decisions to disclose. Serovich et al.'s argument, however, focuses on categories of actual reactions. The present study reveals some similarities (e.g., the category of negative emotional reactions) but the predominant response was the different treatment category of actual response, contrary to reports from Serovich et al. This is clearly an area for future research, perhaps asking participants to participate in a Q-sort task to see how they sort/group actual and expected reactions.

All participants reported negative reactions to disclosure, although not all could be attributed to stigma. The problem of "gossip," in particular, threatens privacy and pervaded participants' stories. Privacy regarding HIV/AIDS is simply not treated the same as for another illness (e.g., would these privacy violations occur in the same way if a woman had cancer or lupus?). It is important to consider women's rights to protect themselves by closing boundaries. One example of closed boundaries was women's fear of gossip and their closed reaction (non-disclosure) to such fears. When women discussed this problem, it was not considered a problem with the target person *knowing* the information; rather, the issue was the target person *telling* others. Women needed to trust that a target person would keep the disclosure private, that the other person would recognize the private nature of the co-owned information (Petronio, 2000, 2002). Again, this reinforces the role of expected response, a contribution of this study and CBM.

Women also constructed disclosure rules as a means of self-protection. Rules about disclosing HIV infection were founded on family role, anticipated response, or

relational quality. For example, women in this study disclosed the diagnosis to boyfriends and generally to mothers (but not fathers). This supports meta-analyses indicating female to female disclosure is particularly high (Dindia, 2002; Dindia & Allen, 1992). African American women also disclosed to other family members, but this was predicated on how close they were to those persons. Some adolescents felt that they "owed it" to their families to tell them. Thus, rules about not disclosing HIV infection were both situational/contextual and personality based, another application and extension of CBM. The choice to disclose to family members if a close relationship exists demonstrates the importance of family to these adolescents and how disclosure rules are predicated on cultural edicts (Kimberly et al., 1995). Information sharing represents a strength of the African American family, illustrated in this study, that is not always easily managed.

For both HIV disclosure and non-disclosure, expected response was significant in making the decision. The only exception to this rule was for boyfriends, and these participants disclosed to boyfriends even if they thought the response would be negative; they felt the disclosure was an important relational expectation and exception. This is in contrast to other targets where if the expected response was strongly negative, women chose not to disclose the diagnosis. In general, these actual responses were slightly more positive than the expected reactions but also included negative reactions unanticipated by women (e.g., violence and gossip). It is important to note that these actual reactions came only from those who had been told; it is possible that the most extreme negative responses might be excluded or underrepresented because some people were not seen as good choices for disclosure.

These data provide new findings not previously studied about choices in *order of disclosure or timing*. Most participants disclosed to their mothers on the first day they found out about their infection, and less often to those accompanying them (e.g., friends) to receive test results. There was a time delay between these initial disclosures and subsequent ones to other targets, a finding that extends CBM by indicating time-order rules exist. CBM previously has not predicted the timing or order of disclosure. This theory implied individuals have different motivations for disclosure depending on their needs (cf. Derlega et al., 2002), and the issue of the timing of disclosure indicates needs are considered. For instance, adolescents told mothers first because of immediate needs such as child-care. Some family members expressed hurt at the delay in disclosure, indicating they felt it was a relational violation to be kept waiting.

Results of this study also indicate that work still needs to be done to decrease stigma associated with HIV/AIDS. Some misinformation about transmission through casual contact remains despite extensive educational efforts (e.g., targets of disclosure who feared sharing ketchup or thought that touching someone with HIV and/or AIDS could be dangerous). Many descriptions of non-disclosure of HIV contain references to stigma. If stigma continues to decrease, perhaps one result would be an increased willingness to disclose. The sex differences reported in the present study provide evidence for the importance of examining both sex of target (Dindia, 2002) and women's disclosure patterns separate from that of men. For example, reports indicate gay men disclose only slightly more to mothers than to fathers (e.g., Greene & Serovich, 1996), but women in this study overwhelmingly disclosed to mothers (and aunts, grandmothers, and sisters). In addition, women targets were told directly but male targets (except boyfriends) tended to be told via a third party. In the future, research should seek to further understand the role of directness of disclosure, such as

whether the third-party disclosure so often reported by these women (especially to male targets) is a strategic choice or is based on lack of skills, avoiding emotional drains, or face management. These sex effects are important to consider, although it is not clear whether these effects are specific to women, an interaction between sex discloser and discloser, or a combination of sex and cultural roles of the women in this study.

After women in this study disclosed, they often received support (e.g., reminders to take medication), sometimes even more than they had anticipated. Some women even reported that friends and family treated them no differently than before the disclosure. However, all women had to contend with such negative reactions as avoidance, different treatment, others telling about the infection, and violence.

Implications

African American young women are clearly different when compared with other populations in terms of HIV disclosure to partners. For instance, gay and bisexual men indicate much less disclosure to both casual and longer-term sexual partners (e.g., Marks et al., 1992; Perry et al., 1990). Women in this study did reveal HIV infection to sexual partners, although not as consistently to ex-partners. Thus, strategies encouraging disclosure of HIV infection to current sexual partners may be treated differently with African American young women. Indeed, several women reported not being sexually active as a result of HIV infection, contrary to reports of increased sexual activity post diagnosis among some groups of men. Women in this study were very concerned that partners know of the infection (several were the source of infection) and the potential risks. Several couples were planning to have children together and made this parenting decision jointly.

On the basis of the findings from this study, HIV-positive women may need to discuss potential reactions to their disclosure of HIV infection and where they might obtain needed support. The women in this study generally were able to accurately predict others' reactions to the disclosure, but they had trouble with problems associated with gossip (i.e., not keeping information private). It is also important to consider the costs of delayed disclosure, as the finding of perceived relational violations ("Why didn't you tell me sooner?") might have long-term effects on relationships. With regard to health effects, encouragement to take medication, ability to "just talk," rides to appointments, and childcare were positive outcomes of disclosure. However, it is also important to be aware of the potential for violence against the supposed source of infection and the possibility that some people refused to discuss or avoid the HIV topic. These reactions might leave an HIV-positive woman without needed social support.

These results can also be used by health care providers such as therapists, social workers, or nurse practitioners, working with HIV-positive young women to assist them in understanding the process of disclosure and its potential effects. However, they must do so while remaining sensitive to cultural issues. For example, these data show that African American women are more inclined to disclose to a broader range of family members than Caucasians (cf., Greene & Serovich, 1996; Kimberly et al., 1995), and they define these families more broadly (e.g., cousins and aunts). In these disclosure decisions, however, relational quality is important. Specifically, it was uncommon for women to tell fathers who were not a part of their lives. Moreover, the fact that older men infected most participants speaks to the need for continued HIV

prevention and education. Power imbalances in these relationships may contribute to difficulty in negotiating safer sex behavior such as condom use.

Limitations

There are several limitations in the present study worth noting, perhaps the most important being the sample size of 10, although the focus here on a different unit of analysis provided rich and varied data. Clearly, a larger sample would provide different opportunities to analyze data, but the focus on the special sample allows for a more detailed exploration of cultural and situational variables. Additionally, there is not yet enough evidence to directly compare the disclosure patterns of these African American young women with other samples. Although this is a growing segment of HIV population, the experiences of African American young women may not generalize to other populations of women, African Americans, or adolescents. The interviews also were conducted with the HIV infected person; thus, perspectives of the disclosure targets were not obtained. Obtaining others' perspectives could lead to better understanding of (and possibly memory of) reactions, timing, and relational quality. Finally, the data were not collected longitudinally and contain those inherent limitations.

Future Research

The number of persons living with AIDS continues to increase (CDC, 1999). For example, deaths decreased 42% from 1996–97 and 20% from 1997–98. With a latency period of up to 10 years, non-disclosure might be even easier with the delayed onset of AIDS symptoms. The beneficial effects of new anti-retroviral treatment, including longer and healthier lives, will result in more relationship decisions, such as disclosure. As people continue to live with HIV infection for even longer periods of time, it will continue to be crucial to explore their relationships. It is possible that, with time, HIV-related stigma will decrease, making these disclosure decisions less troubling, but we are certainly a long way from that reality. The present study adds to our understanding of the HIV disclosure process and how it is managed in relationships. Additional research tracking people across time would be helpful. For example, if a person is expecting a very negative response to the disclosure of her/his infection, does this occur when the person is told (or finds out)? Over time, the reported relational violation finding "Why didn't you tell me sooner?" could be studied to see whether it is a factor in relational quality and how these relationships progressed. This will continue to be a fruitful area for study, not just for HIV/AIDS but also for other difficult disclosure decisions.

NOTES

¹ Language used in reference to the HIV and AIDS epidemic has and will continue to shift. For example, early terms used PWA (person with AIDS), later PLWA (person living with AIDS), and now either HIV-positive or individual with HIV. The terms are complicated because individuals diagnosed with AIDS or AIDS related complex also are HIV-positive, but the reverse is not true, thus HIV/AIDS is a difficult term. Also, we now have individuals who were once diagnosed with HIV and now have no detectable levels of HIV in their blood. For the present paper, we have opted to utilize the term HIV-positive in an effort to be sensitive to these variations.

² CD4 (t-cell counts) and viral load are the most common indicators of HIV and AIDS progression (and some argue that they should be used in conjunction to determine treatment strategies). Standards of care change quickly, but CD4 counts below 200 alone qualify for AIDS diagnoses and indicate increased susceptibility for opportunistic infections (levels below 500 are moderate).

³ Several of these adolescents were pregnant, and others were involved in drug trials. Social workers reported significant difficulty in obtaining funding for the medication. If the interviews were conducted in 2001, it would

be expected that all these women would be on some form of combination therapy. There are, however, additional complications regarding prescribing cocktails to adolescents generally (see Greene & Cassidy, 1999 for a discussion of the ethics of physicians withholding cocktails from adolescents they feel will not comply with a drug regimen).

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