

CHAPTER

NINETEEN

Appropriateness of Disclosure of HIV Testing Information: The Perspective of PLWAs

INTRODUCTION

Kathryn Greene and J. M. Serovich

Disclosure is an important area of communication research because it affects relationships and relationship development. In any relationship, people must weigh choices about what to tell and to whom, but also when and where to tell. Individuals can share the information (disclose, often seen as verbal statements about the self) or choose to remain

closed (maintain privacy), and this process can affect the relationship. There are many reasons to disclose or retain privacy, each with consequences for both the individual and the relationship. For example, the person receiving the information could be shocked or not respond well, or the relationship could evolve to a new level based on trust demonstrated by

sharing difficult information. The theory of privacy presented in this chapter, communication privacy management (Petronio, 1991), describes one view of this disclosure and privacy management process.

This chapter illustrates one particular topic to explore this disclosure process: HIV/AIDS. Despite new medical advances, AIDS is one of the most stigmatized diseases in history. This notion of stigma and spoiled identity (see Goffman) affects choices to disclose an HIV diagnosis. People with HIV (the virus that causes AIDS) must balance carefully their choices to disclose this information (or not). They may, for example, disclose to gain support, to find another to talk with, or to protect the other (e.g., to encourage a sexual partner to use safer sex). On the other hand, people with HIV may choose to remain private or not disclose to avoid negative consequences (e.g., violence or relationship termination), to avoid gossip, or to protect their privacy (e.g., "it's none of their business"). There are many more reasons why peo-

ple would disclose HIV infection or remain private, reflecting the complexity of this issue.

This chapter explores this process of HIV disclosure in two phases. Study 1 compares attitudes toward privacy and sharing HIV-related information for people with HIV and those not reporting having HIV. These two groups reported similar groupings of targets, also described in terms of informational boundaries. Study 2, examines these boundaries using actual disclosure patterns for those with HIV.

After reading this chapter you should be able to reflect on these issues:

- What kind of information is difficult to decide to share or keep private (and to/from whom)?
- How does a decision to disclose (or not) and when affect a relationship?
- Why does HIV/AIDS continue to be such a unique and stigmatized health concern?

The Appropriateness of Disclosure of HIV Testing Information

The Perspective of PLWAs

Kathryn Greene and J.M. Serovich

The incidence of AIDS/HIV infection, accompanied by a rise in HIV testing, has increased dramatically in the past ten years. People who test HIV positive, even those tested for HIV, must deal with issues surrounding disclosure of this sensitive information. As the ranks of those infected swell, there is growing controversy regarding the rights to privacy of HIV-positive individuals on the one hand and the perceived public good (disclosure) of this sensitive information on the other (see: Bayer & Toomey, 1992; Krupla & Vener, 1988; Lang, 1991; Swartz, 1990). As Sun (1987) noted, "because AIDS has been constructed as a disease of unknowns affecting the other, public debate has been most easily framed in terms of individual rights versus the public good" (p. 13). Most Americans see the control of HIV/AIDS as requiring some loss of individual privacy and possible restrictions on civil rights (Blendon & Donelan, 1988).

Despite some literature on the perceived conflict of public and private interests regarding HIV/AIDS, there has been a marked absence of research on the consequences of disclosure of HIV test results for those most directly affected, those who have tested HIV-positive as well as people living with AIDS (PLWAs). This article investigates disclosure

in the context of HIV in two ways: first, it explores PLWAs' perceptions of who should have access to HIV testing information; second, it explores to whom PLWAs disclose their HIV infection

Review of Literature

Little is known about why, to whom, and with what effects people choose to disclose their serostatus. Even with this absence of understanding, policies regulating HIV/AIDS and disclosure continue to be made. For example, third party notification programs are in place in some states, but they may create ethical dilemmas for those involved (see: Bayer & Toomey, 1992; Kernani & Weiss, 1989; Melton, 1988; Swartz, 1990). Identification of people with HIV antibodies has been rationalized as a way to protect unaffected persons from possible transmission of the virus (Silin, 1987).

There is an available model to assist in understanding how HIV-positive individuals might want to regulate information about their serostatus. Using a systems approach, Petronio (1991) proposed a theory of boundary management to describe how people control potential risk to self when disclosing. Petronio described how individuals regulate

disclosure of private information in relationships to attain a balance between disclosure and privacy, between intimacy and autonomy. To achieve this balance, individuals erect metaphorical boundaries to protect themselves and to reduce their chance of losing face. The risks associated with disclosing HIV infection are tremendous, perhaps leading to more rigid boundaries (little or no disclosure) where PLWAs might perceive *any* sharing of information about their disease status as a threat.

One of the strengths of Petronio's model is that it is transactional, focusing in part on why people make decisions to disclose. People use rules or criteria to control boundaries and regulate the flow of private information (Petronio, 1991), yet much work remains to establish how these rules function. In the context of HIV, the most useful information to consider is the factors that affect discloser decisions. Petronio argues there are three discloser factors: expectations of the discloser, message strategy, and message content. It is the expectations of the discloser that are likely to vary by relational type and intimacy, characteristics associated with perceptions of the potential discloser. In this sense, disclosure is strategic.

Yep (1993) applied boundary management theory specifically to the potential vulnerability of disclosure of HIV infection. Yep elaborated on what factors might affect decisions to disclose, especially the balance between a need to receive social support yet avoid the emotional distress and stigma associated with HIV. Although Yep's application of boundary management theory to the context of HIV is intriguing, it has not been fully tested to this point. Greene and Serovich (1995) used boundary management theory to explore disclosure of HIV, and they reported

relational quality and anticipated response were the best predictors (in a non HIV-positive sample) of willingness to disclose information about HIV. The present investigation assessed the utility of boundary management theory in the context of disclosure of HIV infection by focusing on target or role of discloser.

Research on Privacy and HIV Testing

Disclosure is a complex process, and there is a need to adapt what is known about disclosure to the specific context of HIV/AIDS. Research on the process of disclosure also may prove beneficial in understanding how perceptions of privacy function in the context of HIV testing.

Greene, Parrott and Serovich (1993) compared college students and parents perspectives of privacy and appropriateness of disclosure of HIV testing information. Not surprisingly, they found people reported more overall support for access to results of HIV testing information than access to information that someone has been tested for HIV. Overall, findings indicated that attitudes toward disclosure of HIV testing information can be predicted by individual difference variables (e.g., perceptions of privacy, religiosity, and attitude toward homosexuality). In general, people with more accepting attitudes toward homosexuality and more liberal religious beliefs report that others should have less access to information about results of HIV tests.

In addition to research on predictors of individual perceptions of disclosure of information about HIV, research has examined if who the recipient is affects perceptions of appropriateness of disclosure. Researchers have established that the target or recipient of disclosure

constrains how individuals reveal information about themselves (Stokes, Fuchres, & Childs, 1980; Tardy, Hosman, & Bradec, 1981). Individuals delineate clear boundaries among (a) marital, community, and general public groups, and among (b) marital, nuclear, and extended family subsystems in perceptions of appropriateness of disclosure of HIV testing information (Serovich & Greene, 1993; Serovich, Greene, & Parrott, 1992). Specifically, those closer or more intimate are perceived as more appropriate for access to information about HIV, and those with less intimate relationships are perceived as less appropriate for access to this information. This process can be described as an attempt by individuals to create informational boundaries, a process consistent with that described by Petronio's boundary management theory. Some people are simply not viewed as appropriate for having access to information about results of HIV tests. As a result, a semi-permeable boundary may be necessary, such a boundary allows adequate input in the form of education, medical treatment, and social support—input which may be provided without negative consequences such as loss of employment or housing. It is necessary to engage in some self-disclosure to create a social support network. Thus, there may be a need for both privacy and disclosure for adequate functioning.

Using this boundary approach, Serovich et al. (1992) looked at the potential recipient of HIV testing information. It was expected that people viewed as most directly affected by the diagnosis (e.g., spouse, lover) would be seen as more appropriate recipients than those less directly affected (e.g., teachers, employers). Serovich et al. manipulated the target/recipient of the information, for example "Employers should have access to results of employees

AIDS tests," using eleven recipients in Likert-type format. They reported a three-factor solution accounting for 73% of the variance. The "community" factor included employer, potential employer, co-worker, and teacher targets. The "general public" factor included newspapers general public, and community leader targets. The "marital" factor included two targets, lovers and spouses. Two items in these analyses loaded on two factors, classmates and family members. Overall, individuals reported most desire to restrict access to HIV testing information to the general public, less to the community, and least to the marital subsystem.

Serovich and Greene (1993) expanded on this work by looking at potential recipients or targets for access to HIV testing information within families. They reported a three-factor solution accounting for 85% of the variance. The "extended family" factor included the aunt, uncle, cousin, and mother-, father-, sister- and brother-in-law targets. The "nuclear family" factor included mother, father, son, and daughter targets. The "marital family" factor included spouse, former spouse and lover targets. Four targets loaded on two factors (nuclear and extended): sisters, brothers, grandmothers, and grandfathers. Overall, participants reported most support for others' access to HIV testing information to the marital system, moderate to the nuclear family, and least support for access to the extended family.

Taken together, the findings of these studies support the notion that people create informational subsystems in making decisions about who should have access to results of HIV tests. What has not been thoroughly examined is how HIV-positive people perceive access to HIV testing information. It is not known if those most directly affected by

disclosure of this information (PLWAs) create boundaries or subsystems in similar ways. Given that previous researchers found these informational boundaries with other samples, it would be expected that PLWAs would create subsystems in similar ways.

Hypothesis 1: HIV-positive individuals create boundaries based on others' access to results of HIV tests; specifically, those closer to the discloser (marital and nuclear family) are viewed as more appropriate recipients of HIV test results than those not as intimate (extended family, general public, and community).

Privacy and HIV Positive Individuals

Although there has been little research on disclosure and privacy in the context of testing, there has been even less work specifically with HIV-positive individuals. Some research on attitudes of HIV-positive individuals has been published, but some of these studies are more qualitative in nature, using, for example, methodologies of interviews (e.g., Lang, 1991) or case studies (e.g., Carlson, Greeman, & McClellan, 1989; Fleck, 1991). These studies have provided valuable preliminary information that should be further explored.

There are tremendous risks for HIV-positive individuals in disclosing their serostatus. Yep (1993) hypothesized that the stigma associated with HIV was similar to what Goffman (1963) described as "spoiled identity." People with HIV/AIDS are more stigmatized than people with other diseases, such as toxic shock or legionnaires' disease (Hughes, 1986), cancer and coronary disease (Walker, Taylor, & Green, 1990), or leukemia (St. Lawrence, Husfeldt, Kelly, Hood, & Smith, 1990). The

disclosure process for HIV-positive persons may be similar to what has been identified as the risk of disclosing information perceived as negative, such as homosexuality, being raped, or being sexually abused. People with direct experience with any of these sensitive issues may have experienced negative reactions from disclosure of this information. However, disclosure is necessary to receive support and to acquire needed information and assistance. Pennebaker (1989) argues that disclosure of traumatic events is associated with lower overall stress and increased psychological health. Thus, HIV-positive persons must make choices to try to disclose for the benefits yet avoid the negative consequences.

HIV-positive individuals may have more desire to restrict others' access to results of HIV tests because they fear potential negative consequences. For example, they may fear discrimination, such as loss of employment, eviction, losing child custody, and cancellation of insurance (Anderson, 1989). Documentation of this type of discrimination has been difficult, but there is widespread anecdotal evidence. PLWAs also may fear physical abuse, "bashing," particularly PLWAs identified as homosexuals (Anderson, 1989).

HIV-positive individuals also may have a high desire to restrict others' access to results of HIV tests because they are aware of perceptions of HIV/AIDS as a gay disease. According to public perception, many HIV infections are acquired through association with stigmatized activities (e.g., homosexual or bisexual sexual contact and IV drug use). HIV/AIDS, however, has been associated primarily with the homosexual/bisexual population (Robinson, Walters, & Skeen, 1988). Hence, negative attitudes toward HIV/AIDS have been clearly linked to negative attitudes

toward homosexuality (Cohen & Grace, 1988; Kelly, St. Lawrence, Smith, Hood, & Cook, 1987; Larsen, Serra, & Long, 1990; Ross, 1988; Stupp & Kerr, 1989). Marks et al. (1992) reported that virtually no one revealed HIV infection to parents who did not already know their gay/bisexual orientation. People with negative attitudes toward homosexuality also are more likely to support increased access to information about HIV tests (Greene et al., 1993), and increased access might be a potential threat to HIV-positive persons.

Finally, HIV-positive individuals may have more desire to restrict access to results of HIV tests because they are aware of generally negative attitudes toward PLWAs. Researchers have documented general negative attitudes toward people with HIV/AIDS and anxiety over potential contagion by medical personnel (Pleck, O'Donnell, O'Donnell, & Snarey, 1988; Sherr, 1987; Wallack, 1989). Researchers have reported that men generally have more negative attitudes toward HIV/AIDS and PLWAs than women (e.g., Eisler, Eisler, & Lang, 1989; Shrum, Turner, & Bruce, 1989; Walker et al., 1990). Negative attitudes toward PLWAs, however, may be decreasing (Johnson, 1989), although people may not be developing positive or even neutral attitudes toward PLWAs, rather they may be becoming less negative.

HIV-positive individuals may fear three results from others' access to HIV testing information: behavioral consequences, perceptions of HIV/AIDS as a gay disease, and general negative attitudes toward PLWAs. Each of these may explain PLWAs' expected desire for less access to results of HIV tests.

Hypothesis 2: HIV-positive individuals report others should have less access to

HIV testing information than other sample groups for marital, nuclear, and extended family, general public, and community targets.

Disclosure of HIV Infection

Previous research reviewed one part of the disclosure and HIV area—perceptions of who should know about HIV test results—yet little work has examined who actually is told about HIV infection. Attitudes toward disclosure provide significant information, and additional information about boundaries might be gained from examination of actual disclosure practices. Marks et al. (1992) examined disclosure patterns in a sample of HIV-positive Hispanic men and proposed that people with HIV evaluate subjectively the potential consequences of informing a particular target person before a disclosure is made, a process that may be similar to the boundary formation in attitudes described earlier. They did find HIV-positive individuals' expectations about disclosing vary by relational type and level of intimacy. In this study, HIV-positive persons were more likely to disclose their HIV status to more significant others than to less significant others. The lowest rate of disclosure was to employers, landlords, and religious leaders, a higher rate of disclosure was to mothers, siblings, and friends, and the highest rate was to lovers and spouses. In interviews with five HIV-positive women, Kimberly, Serovich and Greene (1995) reported similar high disclosure to partners, parents, siblings, and children (depending on age). It seems clear from these findings that the creation of informational boundaries in disclosure practices may be quite similar to patterns observed in attitudes toward who should know about the results of HIV tests.

Hypothesis 3: HIV-positive individuals disclose their serostatus most to those closer to them (i.e., marital subsystem and nuclear family) and least to those further from them (i.e., the extended family).

Method

Participants and Procedure

Participants in this study consisted of 77 individuals who had been diagnosed HIV-positive and resided in the southwestern portion of the United States. Participants were recruited through two non-profit organizations aimed at servicing the informational, educational, counseling, and referral needs of PLWAs. Participants were recruited in two ways. Some received a questionnaire with a stamped return envelope (response rate was 34%),¹ whereas others were asked to fill out the questionnaire at the center where they received services (no in-person refusals). The questionnaire took approximately 30 minutes to complete and was anonymous.

Participants had known their HPI/positive status, on average, 48.13 months (range 0 to 132 months). The sample was 78% male and ranged in age from 23 to 50 ($M = 33.96$; $SD = 7.05$). In terms of religious preference, 27 reported "none," 9 Catholic, 22 Protestant, and 13 "other" (6 not reported). The sample included 52 Caucasians, 5 African-Americans, 10 Hispanics, and 4 Asian (6 not reported). Fifty-four percent reported being currently unemployed, 24% reported losing their job due to their HIV-positive status.

Measurement Instruments

One construct of interest in this study, perceived appropriateness of others' access to HIV testing information, was measured by a series of Likert-type items. The 26 items consisted of statements such as, "Lovers should have access to information about results of AIDS tests." The items were changed by manipulating the target/potential recipient, and the targets included the following (proposed subsystem in parentheses): spouses, former spouses, lovers, (marital subsystem); sons, daughters, mothers, fathers (nuclear subsystem); aunts, uncles, cousins, mothers-in-law, fathers-in-law, sisters-in-law, and brothers-in-law (extended family); employers, potential employers, co-workers, teachers (community subsystem); community leaders, general public, and newspaper (general public subsystem); classmates, family members, sisters, brothers, grandmothers, grandfathers (previous split loadings). Responses to these items ranged from "Strongly Agree" to "Strongly Disagree," with a higher score indicating less perceived appropriateness of others' access to information about HIV testing or more support for privacy.

Actual disclosure of HIV infection also was measured. Participants were asked, "does x know you are HIV-positive?" A number of targets/recipients used in previous research were excluded due to the length of the questionnaire, and the ten targets retained in this study included the following: significant other; mother, father, first, second and third sibling; maternal grandmother and grandfather; and paternal grandmother and grandfather. Because of the length of the survey, the disclosure questions were limited to the marital and nuclear family targets. It was also necessary to ask if each target person was relevant to the participant (e.g., only children would

not have siblings, or a grandparent might be deceased).

Reliability Previous research indicated the attitude toward disclosure items formed reliable measures by subsystem. Serovich et al. (1993) reported, for a sample of college students and parents, low-to-acceptable reliabilities (alpha range .61-.85). Serovich and Greene (1993) reported, for a sample of married and dating couples, adequate reliabilities (alpha range .75-.98). The only questionable subsystem measure in previous research was the marital subsystem, but the three-item measure (Serovich & Greene, 1993) showed marked improvement over the two-item mea-

sure (Serovich et al., 1993). The reliabilities (Cronbach's alpha) by subsystem for the present study were adequate, ranging from .87 to .98 (see Table 1).

There are several limitations to this study worth noting. First, the sample size is relatively small and over-represents males, potentially affecting the generalizability of findings. The moderate response rate might also be a concern; however, given that some of the target sample were in advanced stages of an AIDS-related disease process, it would be understandable if they did not return the questionnaire. Thus, these data provide some useful insight, but results must be interpreted with these limitations in mind.

Table 19.1. Summary of means, samples, reliabilities, standard deviations and 95% confidence intervals by subsystem for present and comparable past studies

Subsystem	Serovich et al. (1993)	Serovich & Green (1993)	Present Study
Sample of:	Young Adults & Parents (N = 327)	Married & Dating Couples (N = 404)	HIV + Individuals (N = 77)
General Public (3 items)	alpha = .84 $M = 4.14$; $SD = .95$ 95% CI (4.01-4.29)	—	alpha = .92 $M = 4.58$; $SD = .72$ 95% CI (4.34-4.82)
Community (4 items)	alpha = .85 $M = 3.27$; $SD = .95$ 95% CI (3.09-3.45)	—	alpha = .92 $M = 4.58$; $SD = .72$ 95% CI (4.34-4.82)
Extended Family (7 items)	—	alpha = .98 $M = 3.43$; $SD = 1.05$ 95% CI (3.28-3.58)	alpha = .98 $M = 3.59$; $SD = 1.12$ 95% CI (3.20-3.98)
Nuclear Family (4 items)	—	alpha = .95 $M = 2.32$; $SD = 1.05$ 95% CI (2.28-2.48)	alpha = .97 $M = 2.96$; $SD = 1.38$ 95% CI (2.48-3.44)
Marital (2-3 items)	alpha = .61 $M = 1.66$; $SD = .75$ 95% CI (1.54-1.78)	alpha = .75 $M = 1.63$; $SD = .73$ 95% CI (1.48-1.73)	alpha = .97 $M = 2.48$; $SD = 1.15$ 95% CI (2.42-3.26)

Data were analyzed using MANOVAs, factor analyses (varimax rotation), and 99% confidence intervals. The level of significance was set at $p < .05$ for most tests, with an alpha adjustment for the number of tests in Hypothesis 2.

Hypothesis 1

Hypothesis 1 predicted HIV-positive individuals create boundaries among subsystems (general public, community, extended, nuclear and marital) based on desire to allow others' access to information about results of HIV testing. This hypothesis was partially supported. The means by subsystem were all in the expected order, but not all subsystems were significantly different (see Table 19.1). MANOVAs also indicated the presence of three (not five) significantly different subsystems for this sample of HIV-positive individuals. A MANOVA indicated a significant within-subject effect for target or recipient ($F(7,3) = 52.3$; Hotelling's $= 2.92$; $p < .001$); that is, there were perceived differences in appropriateness of disclosure by target.²

An initial factor analysis of all 21 targets (those cleanly loading in previous research) also indicated a three-factor solution, consistent with results of the MANOVA, accounting for 79% variance. The first factor (eigenvalue = 11.53; % Var = 54.9) loaded seven extended family items above .8 (e.g., in law, cousin). The second factor (eigenvalue = 3.67; % Var = 17.5) loaded seven nonfamily items above .6 (e.g., coworker, community leader). The third factor (eigenvalue = 1.47; % Var = 7.0) loaded three nuclear family items above .85 (e.g., spouse, lovers). Four items (son, daughter, mother and father) loaded on both factors 1 and 3, but additional evidence indicated they were better explained

as part of the immediate family subsystem (factor 3).

The previous marital and nuclear family subsystems were not significantly different (by factor analyses, confidence interval, or MANOVA), and these items were combined to form a subsystem labeled "immediate family." The extended family² was significantly different from all other systems, consistent with previous research. The final subsystem, labeled "non-family," was a combination of previous general public and community subsystems. As expected and found in previous research, participants reported most desire for others' access to results of HIV testing information to the immediate family subsystem, next most to the extended family, and least access to non-family members.

Hypothesis 2

Hypothesis 2 predicted HIV-positive individuals, as compared to the general population, report less desire for access to HIV testing information (or more privacy) across all subsystems. This hypothesis was generally supported, as most confidence intervals did not overlap. Table 19.1 presents the means for the present study along with results from two comparable previous studies using different samples. Across the subsystems examined, HIV-positive individuals perceived others should have significantly less access to results of HIV testing information than did members of the general population. There was only one subsystem (extended family) where HIV-positive individuals did not desire more privacy than other groups (confidence intervals were not significantly different). For each of the other four subsystems, HIV-positive individuals reported significantly less desire for access to results of HIV testing information.

Hypothesis 3

Hypothesis 3 predicted more HIV-positive persons report disclosure of their serostatus to the marital and nuclear family and fewer report disclosure to extended family members. This hypothesis was supported. Table 19.2 presents the frequencies and percentages for disclosure of HIV infection by target. It was not possible to make direct comparisons with all subsystems because of what data were collected (focus on actual disclosure to family members). According to these data, there is most disclosure of HIV infection to the immediate family (marital and nuclear subsystems previously) and less to the extended family. Percentages of *who* had disclosed to the immediate family were extremely high (73%–85%), with disclosure to mothers (85%) slightly higher than to fathers (73%). Disclosure to siblings was moderate (range 40%–55%), and disclosure of infection to grandparents was even lower still (range 29%–44%).

The general pattern of these disclosure percentages reveals three groupings similar to the kind of pattern found in attitudes toward disclosure. The highest disclosure was to partners and parents (range 73%–85%), next highest disclosure to siblings (range 40%–55%), with lowest disclosure to grandparents (range 29%–44%). In order to test if these differences in groupings were significant, z-tests for proportions were performed (Hayslett, 1968). If the maternal grandmother was ignored as an outlier, the z-tests between the closest targets in adjacent subsystems approached the critical value of 1.645. Specifically, fathers were significantly different from first siblings ($z = 1.67$), but second siblings were not significantly different from paternal grandmothers ($z = .64$).

Some items in the present study were designed to measure perceptions of others' access to results of HIV tests, consistent with the theoretical approach. It must be noted, however, that this does not assess actual disclosure of HIV infection. In order to examine this relation, correlations were run between actual disclosure (measured as number of target persons disclosed to) and the five subsystems (see Table 19.3). Correlations between the five subsystems and actual disclosure indicated the relations varied in both direction and strength. Correlations between actual disclosure and marital and nuclear family subsystems were inverse; that is, people who had disclosed their HIV infection to more people were less likely to support access to HIV tests for the marital or nuclear family. It may be that disclosure to intimates and immediate family are still viewed as private choices, not sharing that should be automatic. The nonrelation between actual disclosure and extended family is not surprising given that the extended family was the most ambiguous target (neutral) in previous research; thus, we still know little about the extended family. Correlations between actual disclosure and general public and community subsystems were direct; that is, the more a person had disclosed his/her HIV infection the more likely she or he was to support others' access to HIV test results. This relation is understandable when considering the extremes in disclosure: a person who had disclosed to few if any others would be unlikely to support access for non-intimates, but a person who had disclosed to many might have confronted fears of negative consequences and might not see others' access as so threatening. In sum, actual disclosure and perceptions of others' access to HIV tests can inform each other.

Table 19.2. Frequencies and percentages for actual disclosure of HIV infection by target

Target	Knows ^a	Does Not Know	Unsure	Not Relevant
Sig. Other	36/84%	5	2	34
Mother	52/85%	8	1	16
Father	38/73%	13	2	24
Sibling 1	28/54%	24	0	25
Sibling 2	19/40%	29	0	29
Sibling 3	16/55%	13	0	48
Paternal grandfather	4/31%	8	1	64
Paternal grandmother	7/33%	12	2	56
Maternal grandfather	2/29%	3	2	70
Maternal grandmother	8/44%	6	4	59

a. Percentages are calculated after subtracting those who did not have target person not relevant.

Table 19.3. Correlation matrix among subsystems and with actual disclosure

Variable	Marital	Nuclear	Extended Family	General Public
Marital Family	1.00			
Nuclear Family	.68 ^a	1.00		
Extended Family	.46 ^a	.75 ^a	1.00	
General Public	.08	.23 ^b	.47 ^a	1.00
Community	.26 ^b	.24 ^a	.62 ^a	.68 ^a
Actual Disclosure	-.09	-.11	.03	.23 ^b

a. $p < .001$

b. $p < .05$

Discussion

The purpose of this study was to investigate PLWAs' perceptions of appropriateness of others' access to information about HIV and disclosure of their serostatus. Also of interest was how these perceptions might be different from perceptions of people who were not HIV-positive. Results of this study suggest that differences do exist, with PLWAs being

more conservative or restrictive concerning others' access to HIV testing information. This is consistent with findings that HIV-positive persons are highly selective in choosing targets of disclosure (Marks et al., 1992). In this study, PLWAs constructed informational boundaries concerning who should have access to results of HIV testing information. PLWAs grouped targets into three distinct

subsystems, with immediate family members (spouses, former spouses, lovers, sons, daughters, mothers, fathers) being viewed as more appropriate recipients of HIV test results than extended family members (aunts, uncles, cousins, mothers-, fathers-, sisters-, and brothers-in-law), who, in turn, were viewed as more appropriate recipients than non-family members (employers, potential employers, co-workers, teachers, community leaders, general public, and newspaper). These results are consistent with the types of boundaries reported by previous researchers (Marks et al., 1992; Serovich & Greene, 1993; Serovich et al., 1992). There are several possible reasons for these particular groupings or creation of informational boundaries.

First, it is plausible that PLWAs need the support of immediate family members beyond the marital subsystem. In previous studies, participants reported a distinction between the marital and nuclear family subsystems. A re-examination of these data revealed only 39% of respondents in this study reported having a significant other or partner. If a PLWA is not in a significant non-family relationship, he or she might be more likely to see other targets, such as parents and/or siblings, as equally appropriate or necessary targets for disclosure. PLWAs may recognize a need for social support and seek more sources for assistance. Kimberly et al. (1995) provide anecdotal evidence for this need for social support, for example, in child care or reading information about HIV. In order to receive this assistance, PLWAs may need to disclose their HIV-positive status to marital and nuclear family members (immediate family).

It is equally plausible that PLWAs feel uncomfortable portioning out immediate family members to tell, preferring that if one know,

they all know. This might serve several functions. First, it eliminates re-telling family members over time and might save emotional energy needed to deal with this type of disclosure. Second, telling multiple family members provides a mechanism for support for the family members themselves. Thus, PLWAs might see it as a necessity for others to know at the same time. This might be especially important for persons who fear they might have to be the ones providing support for the PLWA. In this instance, not disclosing might be a form of self-preservation. PLWAs also might want to avoid putting family members in awkward positions by having information other family members do not, for example telling a mother but not a father. HIV-positive persons (especially those nonsymptomatic) have described not wanting to worry others or cause stress as additional reasons for not disclosing (Kimberly et al., 1995; Marks et al., 1992).

One possible explanation for PLWAs being more conservative in attitudes toward disclosure (Hypothesis 2) is that they may base their decision on who should have access to HIV testing information on their own need to tell (which includes the goal of disclosure to gain support). Non-PLWAs, however, might base their decision on who should have access to HIV testing information on the other person's need to know. Thus, non-PLWAs may perceive sexual partners as significantly different from other immediate family members because of their potential risk for infection. PLWAs may not make this distinction, or may make it in a different way. The framing of "should have access" items focuses on who has a right to know, not if a person intends to disclose. This also may fail to take into account indirect disclosure, through a third person, inappropriate access to results, or by

observation of health conditions (all of which have become foundations for discrimination suits). It is also possible that more conservative attitudes toward disclosure could merely be a reflection of perceived risk, and PLWAs may clearly be in a better position than non-PLWAs to assess risks of disclosing HIV infection.

What is potentially disturbing about these results is that PLWAs are more conservative about disclosure to the marital subsystem, as seen in the results of Hypothesis 2. PLWAs do not perceive spouses, former spouses, or lovers as appropriate recipients of disclosure in the same way as other sample groups. This is disturbing because it would be hoped that disclosure of HIV infection to intimate others would happen automatically. In fact, a major goal of partner notification programs is to reduce the spread of HIV. PLWAs may have difficulty developing and/or maintaining primary relationships; specifically, they may fear their partners would leave if their HIV status were disclosed. Thus, PLWAs may put off disclosure until the relationship has developed further. Studies have generally reported disclosure by HIV-positive persons to sexual partners to be around 50% or less (e.g., Marks, Richardson, & Maldonado, 1991), and Marks et al. (1991) reported disclosure of HIV infection to sexual partners *decreased* in direct proportion to the number of partners.

In the present study, 84%, a much higher percentage, of those PLWAs who reported having significant others had disclosed their serostatus. It is also possible that figures from previous studies were not adjusted for whether the respondent had a significant other (the unadjusted figure for this study is 47%, much like previous reports).

For the purposes of this study, it would be erroneous to conclude that intimate others are not told or to speculate about the time frame in which PLWAs might disclose their HIV-positive status to the marital subsystem or others. What these things might better represent is a recognition of the unpleasantness associated with this kind of disclosure. This is especially true considering PLWAs consistently saw other subsystems as less appropriate targets than other sample groups (cf. Serovich et al., 1992; Serovich & Greene, 1993). Thus, PLWAs' hesitancy to disclose HIV-positive test results is not isolated with the marital subsystem but permeates *all* subsystems.

The patterns for actual disclosure of serostatus (Hypothesis 3) were similar to patterns in attitudes toward who should have access to this information in this study. This provides some evidence that attitudes, behavioral intentions, and behavior are closely related in this context. Most PLWAs in this study had disclosed their infection to their significant other, mother, and father (if they had these persons in their lives). Interestingly, disclosure to mothers (85%) was higher than to fathers (73%), consistent with differences reported by Marks et al. (1992), although percentages in this study were much higher. This finding is consistent with reports that women receive more disclosure overall than men (Jourard, 1961; Jourard & Lasakow, 1958; Jourard & Richman, 1963), and that people disclose more to mothers than fathers (Daltoso, 1972; Komarovsky, 1974; Riverbark, 1971). Gender differences in disclosure, however, are dependent on the dimension of disclosure studied, such as amount versus intimacy (cf. Dindia & Allen, 1992).

Roughly half of the participants in this study had disclosed their infection to siblings

(if they had siblings). This is slightly higher than the 30–34% disclosure to siblings reported by Marks et al. (1992), but this also may be a function of the passage of time between the studies. Roughly one third of these participants had disclosed their infection to grandparents, but extended family members have not been included in previous studies addressing actual disclosure. These targets form only rough approximations of targets or recipients in families (e.g., they do not fit well for people with nontraditional family forms or "families of choice" dominated by extensive friendship networks); however, the same kinds of informational boundaries described by other researchers in disclosure and attitudes toward closure of HIV infection are clear (Marks et al., 1992; Serovich & Greene, 1993; Serovich et al., 1992).

Implications

One widely publicized health recommendation has been for HIV-positive persons to disclose their serostatus, especially to those who might be or have been at risk for infection; thus, however, is a more complex process than previously recognized. Results of this study provide useful information for people designing messages to persuade HIV-positive persons to disclose their serostatus and reduce their risk behavior. First, results confirm that PLWAs have more restrictive attitudes than other sample groups; that is, they are more protective of privacy in this context. Message designers may choose to focus not only on the marital subsystem but the nuclear family to encourage disclosure. In this study there were no differences in attitudes toward disclosure to the immediate family (between the marital and nuclear systems). It may be useful to target parent(s) or children as sources of social

support because these decisions are not generally tied to questions of the recipient's risk for infection.

Currently, health messages to promote disclosure of HIV infection are infrequent (with the exception of those at HIV testing sites); these messages simply recommend that HIV-positive persons disclose to those who might be at risk for infection. These current messages are simplistic and fail to recognize the complexity of this process. Messages, perhaps utilizing a PLWA or the spouse/partner of a PLWA as a source, could use role plays or depict people in the process of disclosing their serostatus. Such messages might be most effective if they emphasize both the positive and negative consequences of disclosure, and this could be done by focusing on the intrapersonal process of deciding to disclose before an actual disclosure scene. Reframing messages from a duty to disclose (public health) frame to what can be gained by disclosing (social support) would be another avenue for message designers.

Results of this study also have implications for professionals in contact with PLWAs, for example, therapists and social workers. Clearly, PLWAs have difficult decisions about disclosing their serostatus, and they are reluctant to do so in some cases. Therapists may want to encourage discussions about disclosure decisions and the process of obtaining social support. Therapists and social workers must be aware that disclosure to spouse/initiator other should not be assumed. It may be that the extended family holds the most difficult decisions, since PLWAs overall reported that immediate family members generally should know and non-family members generally should not know results of HIV tests; attitudes toward disclosure to extended family

members were ambiguous (siblings and children might be especially problematic).

Implications for theory This study provides information for examination of the utility of boundary management theory. One significant component of boundary management theory concerns the expectations of the discloser. Disclosure implies the anticipation of a response from a partner (the disclosee). In this study, the relationship with the discloser (e.g., mother, sister, grandparent) was a significant determinant of whether PLWAs thought others should have access to information about HIV tests. From the perspective of the discloser, Petronio's (1991) description of the role of intimacy and relational level in expectations of the discloser is a valid one. Greene and Serowich (1995) reported the best predictors of willingness to disclose HIV-infection to various family members were anticipated response and relational quality, both components of boundary management theory. PLWAs do indeed create informational boundaries in their perceptions of access to sensitive information and in actual disclosure practices. Additional work to test components of Petronio's theory and Yeps's (1993) application would be fruitful.

There are other theories that could be useful for understanding the process of disclosure of HIV. Uncertainty reduction theory (Berger & Calabrese, 1975) is a way to explain how people are motivated to communicate in order to understand. This theory may be a unitary perspective for explaining how communication affects individuals' perceptions of support (Albrecht & Adleman, 1984): disclosure of HIV could simply be a way to reduce anxiety. One fundamental impact of support has been to reduce uncertainty

over difficult experiences. Other theories recognize social support as critical to handling life stress, crisis and illness (Albrecht & Adleman, 1984), and people may disclose HIV-infection to gain social support. From this perspective, the most effective support may come from those who share the context (cf. Albrecht, 1982), and this would lend credence to the use of support groups for PLWA (or partners, children, etc.) as a place to vent and validate feelings.

Future Research

There are a number of ways in which further research could add to understanding of PLWAs' perceptions of others' access to HIV testing information and their disclosure practices. PLWAs (and their families) must be included in future samples as they are most directly affected by others' access to this information. It would be useful to continue to study just who PLWAs do disclose to, and this may be informed by structured interview methods. Other information about PLWAs' discussions about the disclosure process itself also would be beneficial. For example, it would be worthwhile to study reasons why certain persons were/were not told, their responses, and who told them. Ideally, research could be undertaken from a developmental perspective to see if disclosure patterns change through the disease process. Looking at the timing of the disclosure (e.g., who was told first and how she or he reacted) might reveal relationships between timing and adjustment to the diagnosis. Kimberly et al. (1995) indicated, for HIV-positive women, there may be an initial adjustment period after the diagnosis when no disclosure occurs. Marks et al. (1992) reported disclosure increased with severity of disease (independent of length of

time since testing seropositive), perhaps indicating a need for more instrumental kinds of social support.

Further research should be grounded in coherent theoretical perspectives. Boundary management theory, for instance, suggests message strategy and message content influence disclosure. Other theoretical approaches that focus on relationships, such as social net-

Endnotes

1. It is difficult to estimate a precise return rate with these data. The mailing list used was drawn from the client lists of these two organizations. Thirty-four percent of the surveys returned were usable. An additional 16% were returned but not used because they were either incomplete or not filled out properly. In addition, an unknown percentage of surveys were sent to persons who were deceased, who were hospitalized, or who were too ill to complete the survey.
2. An additional analysis was conducted to see if age of participant and/or length of time known HIV-

References

- Albrecht, T. L. (1982). Coping with occupational stress: Relational and individual strategies of nurses in acute health care settings. In M. Burgeon (Ed.), *Communication Yearbook 6* (pp. 832-849). Beverly Hills: Sage.
- Albrecht, T. L., & Adleman, M. B. (1984). Social support and life stress: New directions for communication research. *Human Communication Research, 11*, 3-32.
- Anderson, E. A. (1989). Implications for public policy: Towards a pro-family AIDS social policy. In E. Macklin (Ed.), *AIDS and families* (pp. 187-228). New York: Harrington Park Press.
- Baye, R., & Toomey, K. E. (1992). HIV prevention and the two faces of partner notification. *American Journal of Public Health, 82*, 1158-1164.
- Berger, C. R., & Calabrese, R. (1975). Some explorations in initial interaction and beyond: Toward a developmental theory of interpersonal communication. *Human Communication Research, 2*, 99-112.
- Blendon, R. J., & Donelan, K. (1988). Discrimination against people with AIDS. *New England Journal of Medicine, 319*, 1072-1076.
- Carlson, G. A., Greenman, M., & McClellan, T. A. (1989). Management of HIV-positive psychiatric patients who fail to reduce high-risk behaviors. *Hospital and Community Psychiatry, 40*, 511-514.
- Cohen, L., & Grace, E. (1988). Attitudes of dental faculty toward individuals with AIDS. *Journal of Dental Education, 53*, 199-207.
- Daluiso, V. E. (1972). *Self-disclosure and perceptions of that self-disclosure between parents and their teenage children*. Unpublished doctoral dissertation, American International University.
- Dindia, K., & Mien, M. (1992). Sex differences in self-disclosure: A meta-analysis. *Psychological Bulletin, 112*, 106-124.
- Eiser, C., Eiser, J. R., & Lang, J. (1989). Adolescent beliefs about AIDS prevention. *Psychology and Health, 3*, 287-296.

- Fleck, L. (1991). Please don't tell. *Hastings Center Reports*, 21, 39-40.
- Greene, K., Parrott, R., & Serovich, J. M. (1993). Privacy, HIV testing, and AIDS: College students' versus parents' perspectives. *Health Communication*, 5, 59-74.
- Greene, K., & Serovich, J. M. (1995, November). *Predictors of willingness to disclose HIV infection to nuclear family members*. Paper presented at the annual meeting of the Speech Communication Association, San Antonio, Tx.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Hayslett, H. T. (1968). *Statisticians made simple*. Garden City, NJ: Doubleday.
- Hughes, J. D. (1986, May). *Mobilizing interventionists to help people with AIDS*. Paper presented at the meeting of the International Communication Association, Chicago, IL.
- Johnson, S.D. (1989). Discrimination against AIDS victims. *Psychological Reports*, 64, 1261-1262.
- Jourard, S. M. (1961). Age and self-disclosure. *Merrill-Palmer Quarterly*, 7, 191-197.
- Jourard, S. M., & Laslow, P. (1958). Some factors in self-disclosure. *Journal of Abnormal Social Psychology*, 56, 91-98.
- Jourard, S. M., & Richman, P. (1963). Disclosure output and input of college students. *Merrill-Palmer Quarterly*, 9, 141-148.
- Kelly, J. A., St. Lawrence, J. S., Smith, S., Hood, H. V., & Cook, D. J. (1987). Medical students' attitudes toward AIDS and homosexual patients. *Journal of Medical Education*, 62, 549-556.
- Kernani, E. J., & Weiss, B. A. (1989). AIDS and confidentiality: Legal concept and its application in psychotherapy. *American Journal of Psychotherapy*, 43, 25-31.
- Kimberly, J. A., Serovich, J. M., & Greene, K. (1995). Disclosure of HIV-positive status: Five women's stories. *Family Relations*, 44, 316-322.
- Komarovsky, M. (1974). Patterns of self-disclosure of male undergraduates. *Journal of Marriage and the Family*, 36, 677-686.
- Kupka, L. R., & Vener, A. M. (1988). College student attitudes toward AIDS carriers and knowledge of the disease. *College Students Journal*, 22, 263-269.
- Lang, N. C. (1991). Difficult decisions: Ethics and AIDS. *Journal of Sex Research*, 28, 249-262.
- Larsen, K., Serra, M., & Long, E. (1990). AIDS victims and heterosexual attitudes. *Journal of Homosexuality*, 19, 103-116.
- Marks, C., Bunde, N. I., Richardson, J. L., Ruiz, M. S., Maldonado, N., & Mason, H. R. C. (1992). Self-disclosure of HIV infection: Preliminary results from a sample of Hispanic men. *Health Psychology*, 11, 300-306.
- Marks, G., Richardson, J. L., & Maldonado, N. (1991). Self-disclosure of HIV infection to sexual partners. *American Journal of Public Health*, 81, 1321-1332.
- Malon, C. B. (1988). Adolescents and prevention of AIDS. *Professional Psychology: Research and Practice*, 19, 403-409.
- Pennabaker, J. W. (1989). Confession, inhibition, and disease. In L. Berkowitz (Ed.), *Advances in experimental social psychology* (Vol. 22, pp. 211-244). New York: Academic Press.
- Petronio, S. (1991). Communication boundary management: A theoretical model of managing disclosure of private information between marital couples. *Communication Theory*, 1, 311-335.
- Pleck, J. H., O'Donnell, L., O'Donnell, C., & Snarey, J. (1988). AIDS-phobia, contact with AIDS-related job stress in hospital workers. *Journal of Homosexuality*, 15, 41-54.
- Riverbark, W. H. (1971). Self-disclosure patterns among adolescents. *Psychological Reports*, 28, 35-42.
- Robinson, B. E., Walters, L. H., & Sreen, P. (1988). Response of parents to learning that their child is homosexual and concern over AIDS: A national study. *Journal of Homosexuality*, 18, 59-80.
- Ross, M. W. (1988). Components and structure of attitudes toward AIDS. *Hospital and Community Psychiatry*, 39, 1306-1308.
- Serovich, J. M., & Greene, K. (1993). Perceptions of family boundaries: The case of disclosure of HIV testing information. *Family Relations*, 42, 193-197.
- Serovich, J. M., Greene, K., & Parrott, R. (1992). Boundaries and AIDS testing: Privacy and the family system. *Family Relations*, 41, 104-109.
- Sher, I. (1987). An evaluation of the UK government health education campaign on AIDS. *Psychology and Health*, 1, 61-72.
- Shrum, J. C., Turner, N. H., & Bruce, K. (1989). Development of an instrument to measure attitudes toward acquired immune deficiency syndrome. *AIDS Education and Prevention*, 1, 222-230.
- Sun, J. C. (1987). The language of AIDS: Public fears, pedagogical responsibilities. *Teachers College Record*, 89, 3-19.
- Shipp, H., & Kerr, D. (1989). Determinants of public opinion about AIDS. *Public Opinion Quarterly*, v. 53, 98-106.
- St. Lawrence, J. S., Husfeldt, B. A., Kelly, J. A., Hood, H. V., & Smith, S. (1990). The stigma of AIDS: Fear of disease and prejudice toward gay men. *Journal of Homosexuality*, 19, 85-99.
- Stokes, J., Fuehrer, A., & Childs, L. (1980). Gender differences in self-disclosure to various target persons. *Journal of Counseling Psychology*, 27, 192-198.
- Swartz, M. (1990). Is there a duty to warn? *Human Rights*, 17, 40-45.
- Tardy, C. H., Hosman, L.A., & Bracke, J. (1981). Disclosing self to friends and family: A reexamination of initial questions. *Communication Quarterly*, 29, 263-268.
- Walker, F. H., Taylor, A. W., & Green, D. E. (1990). Attitudes toward AIDS: A comparative analysis of a new and negative stereotype. *Social Science and Medicine*, 30, 549-552.
- Wallack, J. J. (1989). AIDS anxiety among health care professionals. *Hospital and Community Psychiatry*, 40, 507-510.
- Yep, C. A. (1993, November). *Disclosure of HIV infection to significant others: A communication boundary management perspective*. Paper presented at the meeting of the Speech Communication Association, Miami, FL.