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A TEST OF TWO HIV DISCLOSURE THEORIES

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Abstract

The purpose of this study was to examine two theories of HIV disclosure. The first is a disease progression theory and the second is the theory of competing consequences. Participants were 138 HIV-positive gay men involved in a larger study of HIV disclosure. Structural equation modeling was used to analyze each model, with the root mean square error of approximation (RMSEA) and the nonnormed fit index (NNFI) used to evaluate goodness of fit. The RMSEA for the disease progression model was .031 and the NNFI was .932. The RMSEA for the consequences model was .018 and NNFI was .978. Both indices are considered to be a close fit; however, the parameter estimates for disease progression to disclosure in the disease model and disease progression to consequences in the consequences model were nonsignificant, suggesting that disease progression may not play a role in the decision to disclose an HIV diagnosis. Researchers may want to focus on the intentions and possible outcomes from disclosure as predictive factors.

Understanding what promotes disclosure of an HIV diagnosis to partners, friends, and family is important for a number of reasons. First, disclosure to at-risk partners permits them to play a greater role in either allowing or not allowing unsafe sexual or drug-sharing behavior to occur. Thus disclosure could be a pivotal factor in reducing the behaviors that continue the spread of HIV (Marks, Richardson, & Maldonado, 1991). Second, because disclosure is a necessary prerequisite for acquiring social support, revealing ones' serostatus becomes an important mental health factor. For example, researchers have documented that persons experiencing stress who also disclose tend to feel better emotionally than those who do not disclose (Derlega, Metts, Petronio, & Margulis, 1993; Greenberg & Stone, 1992). It has also been demonstrated that suppressing thoughts or communication about difficult experiences can increase the likelihood of stress-related problems (Greenberg & Stone, 1992; Pennebaker & Beall, 1986; Pennebaker, Colder, & Sharp, 1990). Finally, individuals disclosing to friends and family who provide helpful links to education, health care, and the needed social support also demonstrate improved physical health. Support for this comes from the medical literature where it has been documented that the acquisition of social support, especially from family members, is important for patient adherence to medical regimens (Fennell, Foulkes, & Boggs 1994; Hart, Einav, Weingarten, & Stein, M., 1990; Stuart & Davis, 1972; Wilcox, Gillian, & Hare, 1965).

The most commonly held theory of HIV disclosure contends that disease progression triggers disclosure (Babcock, 1998; Hays et al., 1993; Kalichman, 1995). Because of changes in HIV therapies, however, individuals are not exhibiting a standard pattern of declining health; thus

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disease progression may no longer be a component of the disclosure process. An alternative theory proposes that disclosure occurs after careful deliberation of the positive and negative consequences associated with the event. The purpose of this study is to test the utility of these two theories.

THEORIES OF HIV DISCLOSURE

DISEASE PROGRESSION THEORY

According to the disease progression theory, individuals disclose their HIV diagnosis as they become ill because when HIV progresses to AIDS they can no longer keep it a secret (Babcock, 1998; Kalichman, 1995). Disease progression often results in hospitalizations and physical deterioration, which, in some cases, mandates individuals to explain their illness (Kalichman, 1995). Not only would hospitalization require explanation, but if death is imminent or individuals fear they will need additional assistance to manage their illness, they may disclose as a means of accessing additional needed resources (Holt, Court, Vedhara, Nott, Holmes & Snow, 1998). Delaying disclosure may be a way to normalize their life and protect others from pain (Babcock, 1998).

The relationship between disease progression and disclosure has been substantiated in numerous studies using various indexes of disease progression (Hays et al., 1993; Marks, Bundek, et al., 1992; Marks, Richardson, et al., 1992; Mason, Marks, Simoni, Ruiz, & Richardson, 1995). For example, Marks, Bundek, and colleagues (1992) documented in a study of Hispanic men that as overall symptom severity increased, disclosure to others increased. This trend remained consistent for both overt and less overt symptoms as well as various targets of disclosure such as parents and siblings. Using a sample of symptomatic and asymptomatic men, Hays and colleagues (1993) found asymptomatic men were less likely to disclose their HIV status to family and friends than symptomatic men. Furthermore, disease severity and time since testing for HIV have both been shown to be positively related to disclosure (Mason et al., 1995). Marks, Bundek, and their collaborators (1992) hypothesized that "illness progression heightens anxiety and need for social support, which may motivate disclosure to significant others" (p. 305).

Mansergh, Marks, and Simoni (1995) used both time since diagnosis and symptomology to investigate the relationship between disease progression and disclosure and found significant differences. That is, rates of disclosure were found to be higher among symptomatic than asymptomatic men and disclosure increased with time since diagnosis. These differences were significant for disclosure to mothers, fathers, sisters, brothers, and friends and has provided the most compelling evidence for the disease progression theory.

Studies of disease progression and disclosure of HIV status to sexual partners, however, have failed to find this same relationship (Mansergh et al., 1995). For example, Perry and colleagues (1994) did not find a relationship between severity of physical symptoms and disclosure to sex partners among 129 HIV-positive adults. Thus, while disclosure to family may be influenced by disease progression, disclosure to sexual partners may not be.

CONSEQUENCE THEORY

The consequence theory of HIV disclosure is author derived and suggests that the relationship between disease progression and disclosure is moderated by the consequences one anticipates resulting from the disclosure. That is, as the disease progresses, stresses accumulate which result in the need to evaluate the consequences of disclosure. Persons with HIV are likely to reveal to significant others and sexual partners once the rewards for disclosing outweigh the associated costs.

This theory employs core assumptions of social exchange theory (Thibaut & Kelley, 1959). Social exchange theorists maintain that individuals avoid costly relationships and interactions and seek rewarding ones to maximize the profits in their relationships or behaviors (Thibaut & Kelley, 1959). More specifically, when individuals are faced with numerous choices they tend to make those which provide the most rewards with the least associated costs. Rewards are "pleasures, satisfactions, and gratifications the person enjoys" (Thibaut & Kelley, 1959, p. 12) and include social, physical, psychological, or emotional dividends that satisfy or please. Costs are things of value that are relinquished in preference for an alternative reward that is of equal or greater value or something that would be punishing or distasteful that one would otherwise avoid.

For persons with HIV, consequences of disclosing are substantial. Sharing an HIV-positive diagnosis can provoke feelings of anxiety and threats to personal well-being. As Bolund (1990) stated when discussing cancer, "There is only one disease, AIDS, that has a similar strong attribution of dread" (p. 13). Negative social consequences external to the HIV-positive individual, such as fear expressed by others, ostracism, and degradation may be experienced. Costs in terms of stressors within the individual's family network, such as denial, anger, guilt, and uncertainty are also associated with HIV (Frierson, Lippman, & Johnson, 1987; Herek & Glunt, 1988; Macklin, 1988). Negative emotional consequences of disclosure that have been documented include rejection, abandonment, and isolation (Lovejoy, 1990; Stulberg & Buckingham, 1988; Zuckerman & Gordon, 1988). This might be especially true if the disclosure also leads to an admission of sexual or drug-using behaviors that have not otherwise been acknowledged. In addition, these physical, social, and emotional consequences can be confounded by fear of, or actual loss of, employment, insurance, housing, medical services, child custody, and the right to education (Anderson, 1989; Herek & Glunt, 1988; Zuckerman & Gordon, 1988).

Rewards or positive consequences of disclosing can also be substantial. Disclosing an HIV diagnosis can result in the acquisition of emotional, physical, and social resources. These resources include assistance with home-related chores and errands, health and child care, housing, medical attention, and the provision of medical information. Emotional benefits include the acquisition of social support and acceptance. Furthermore, disclosing one's serostatus frees the individual from hiding complicated medicine taking rituals from friends, family, and coworkers. Thus, indirectly, support for adhering to medical regimens is a positive consequence of disclosure. Each of these consequences may be important for the physical, emotional, and social functioning of the person.

Support for this consequence theory has begun to emerge from the work of prominent disclosure and HIV theorists. These authors contend that individuals who are HIV-positive contemplate the need for privacy and disclosure in determining whether to disclose an HIV-positive diagnosis (Derlega et al., 1993). Derlega, Lovejoy, and Winstead (1998) tested and found support for this hypothesis in a qualitative study of 42 HIV-positive individuals. They concluded that the process of reducing risks and increasing benefits of disclosure results in selectivity of disclosure. That is, HIV-positive individuals disclose to those who pose little risk while avoiding disclosing to those who could harm them.

The purpose of this study is to test the disease progression and consequences theories of HIV disclosure. Each is depicted in Figure 1.

METHODS

PARTICIPANTS

Participants for this study were 138 HIV-positive gay men recruited from an AIDS clinical trials unit associated with a large Midwestern university who were part of a larger HIV and disclosure study. Data for this study came from Wave 1 of a seven-wave longitudinal study. Potential participants were approached by attending physicians and medical staff at the time of their regularly scheduled appointments. After consent was provided, participants completed paper-and-pencil measures before meeting with a trained interviewer who verbally administered an adaptation of Barrera's (1982) Arizona Social Support Interview Schedule (ASSIS). The paper-and-pencil measures took approximately 30 minutes to complete and the interviews lasted between 40 and 60 minutes. Participants were paid \$25.

Participants were primarily Caucasian (71%) men between the ages of 21 and 61 ($M = 38.2$ years, $SD = 7.49$) and contracted HIV from unsafe sexual practices (75.9%). The sample was divided between partnered (31%), single (56%) and dating (13%). More than 60% of the participants were employed, earning an average income of more than \$20,000. These were reasonably educated men with 31% completing high school, 25% either in college or with some college credit, and 20% with at least a college degree. Fifty-seven percent had an AIDS defining illness.

INSTRUMENTS

Disclosure, or whom participants have told they are HIV-positive, was measured using an adaptation of Barrera's ASSIS. The ASSIS consists of a series of questions tapping seven dimensions of a social support network. Participants were asked who they would talk to about things that are personal and private and who they would go to for advice, money, socializing, positive feedback, and physical assistance. In addition, they were asked with whom they have had negative interactions (i.e., arguments or fights). To assess number of sexual partners, participants were asked whom they had sex with in the past 6 months. After a list of social network members was assembled, the interviewer asked if there were other family members not mentioned as a part of the social network. Finally, demographic information on each person including whether the person had been told of the diagnosis was obtained. Then, for each participant, the percent of family members, friends, and sexual partners disclosed to was calculated. Correlations among the three indicators of disclosure ranged from .01 to .20.

For this project, family members include all persons related by blood, marriage, or adoption. Participants averaged five family members ($SD = 2.8$) in their social networks with an average of 55% being told of the diagnosis. Participants also reported an average of four friends ($SD = 3.29$) in their social networks with an average of 63% being told of the diagnosis. Sexual partners included steady relationships (e.g., lovers, partners, boyfriends) as well as past sexual partners and casual partners (e.g., tricks or flings). Participants with steady partners were included because only 75% of partners considered "steady" had been told. In addition, those who reported having a steady partner in the past 6 months also reported having more than one such relationship ($M = 1.60$, $SD = 1.50$). Furthermore, these men reported an average of almost one casual partner ($M = .82$, $SD = 1.75$). Thus many men who reported having a steady partner were also sexually active with other men. Overall, participants reported an average of three sexual partners ($SD = 3.2$) in the past 6 months.

Consequences of disclosure was measured with an 18-item, author-derived instrument. Participants were asked how important each of a list of possible consequences concerning disclosure was to them when considering disclosing to the specific person. Consequences were categorized into 10 reward ($\alpha = .79$) and 8 cost ($\alpha = .84$) items. For example, fear of being

blamed for contracting HIV was a negative consequence of disclosing to that person whereas believing that disclosing would bring the relationship closer is a positive consequence. See Table 1 for item and scale means and standard deviations.

Three measures of disease progression were utilized. First, time since HIV diagnosis was recorded in months ($M = 7$ years, $R = 1$ month - 16 years, $SD = 4.5$ years). Second, the number of opportunistic infections was obtained from the participant ($M = 4.6$, $R = 0 - 16$, $SD = 4$). Finally, a self-reported severity rating for each opportunistic infection was obtained ($M = 3.25$, $SD = .72$).

RESULTS

Structural equation modeling, via analysis of correlation structures provided Systat's RAMONA program, was used to analyze the models in Figure 1. In essence, the analysis was a more traditional path analysis, but using RAMONA allows all paths to be estimated simultaneously rather than in a series of regressions. Furthermore, RAMONA more accurately uses correlation matrices rather than covariance matrices required by the more popular LISREL program. Root mean square error of approximation (RMSEA) and Nonnormed fit index (NNFI) were used to evaluate goodness of fit.

The disease progression model contained one exogenous variable (disease progression) with three indicators and one endogenous variable (disclosure) with three indicators. For this model, a correlation matrix of six variables was entered as the input matrix. The consequences model contained one exogenous variable (disease progression) with three indicators and two endogenous variables (consequences and disclosure) with three disclosure indicators and two indicators for consequences. For this model, a correlation matrix of eight variables was entered as the input matrix. Then, via maximum likelihood iterative method, parameter estimates were calculated for paths and disturbance terms in both models. The null hypothesis for each model was that there is no significant difference between the original matrix of correlations and the reproduced correlation matrix.

The RMSEA for the disease progression model was .031 (confidence interval [CI] = .000, .108), which is considered to be a close fit but with a very large confidence interval. In addition, the chi-square test of the model fit was nonsignificant, $\chi^2 = 9.025$, $df = 8$, and the NNFI = .932. Although the disease progression model appears to be an acceptable model, attention to the parameter estimates shows some irregularities. First, examination of the structural model reveals that the parameter estimates for disease progression to disclosure is nonsignificant, $\beta = .151$, $t = 0.85$ (Table 2). Thus disease progression may not be as predictive of disclosure of HIV status as commonly believed. In addition, parameter estimates for the measurement model show that all measured latent variables loaded significantly on the disease progression latent predictor variable but not the disclosure variable. In fact, although the disclosure variable appears to be poorly measured in this model, this does not hold true for the consequences model.

The RMSEA for the consequences model was .018 (CI = .000, .077) which is considered a close fit. The chi-square test of the model fit is nonsignificant, ($\chi^2 = 18.770$, $df = 18$, and the NNFI = .978). An examination of the structural model reveals that the hypothesized path from disease progression and consequences is nonsignificant, $\beta = -.042$, $t = -.50$; however, the path from consequences to disclosure is significant, $\beta = -.473$, $t = 3.21$. This suggests that although disease progression is not a precursor to consequences, consequences are predictive of disclosure. An examination of the measurement model reveals that all measured latent variables loaded significantly on the disease progression latent predictor variable, and all but one variable loaded on disclosure. Here the percentage of sexual partners disclosed to did not load significantly on disclosure.

Because disease progression did not significantly contribute to either model, the consequences model was analyzed omitting the path of disease progression to consequences. The RMSEA for the revised consequences model was .032 (CI = .000,.136), which is considered a close fit. The chi-square test is non-significant ($\chi^2 = 4.562$, df = 4) and NNFI = .957.

DISCUSSION

When the HIV/AIDS epidemic was in its infancy, the progression of the disease was unambiguous. Individuals contracted HIV, the virus rapidly developed into AIDS, and the individual quickly died. The disease had menacing consequences (i.e., Kaposi's sarcoma), which produced physical manifestations of the disease such as lesions and extreme weight loss. Concealing a diagnosis from close family and friends under these conditions was difficult. For many, advanced therapies have changed the progression of HIV and without the linear progression of HIV to AIDS individuals are living longer, healthier, and more productive lives. Although the outward physical manifestations of the disease have for many been curtailed, the uncertainty of the disease trajectory may have increased. It is plausible that disclosure has isomorphically reflected a trend of being uncertain of when and to whom to disclose.

Other plausible explanations for the lack of support for the relationship between disease progression and disclosure are equally compelling. First, in previous studies disease progression has been measured in a variety of ways including indices of symptom severity, CD4 counts and length of diagnosis, yet these are all very different indices. How one feels (symptom severity) and how one's body is reacting (CD4 counts or viral loads) are different from how long one has been diagnosed. In fact, for many they are distinctly different, may not correlate, and thus researchers may not be measuring "disease progression" as previously conceptualized.

It is also plausible that the methods used in this and other studies have been flawed. For example, a better methodology would be to track individuals as they are diagnosed and monitor under what conditions they choose to disclose. Such a design would allow monitoring of the process in real time so that objective evaluations of the process can be assessed as opposed to relying on retrospective data.

In this study, the consequences theory of disclosure was well supported. This finding suggests that rewards and costs of disclosure to family and friends are assessed before disclosure occurs. What is not known, however, is how this process occurs, how factors are weighed, and outcomes generated. Frequencies of consequences reported in Table 2 provide some insight into what may be influential. From this it can be discerned that the more important rewards were keeping others safe, receiving understanding, and obligation to disclose. These suggest that consideration for others is important in deciding to tell others. Important costs included fear of a fight, lecture, or blame, suggesting that these men may be seeking to protect themselves from further hurt or anger from others. Studies focusing on these outcomes, and perhaps identifying more important or influential ones along with their impact on disclosure, are needed to further understand the mechanism at work.

Neither theory proved to be very predictive of disclosure to sexual partners. The most obvious reason is that the author derived measure of consequences may be inadequate. In fact, the measure was designed to be global and not specific to any particular target. Given that sexual partners are a uniquely different relationship than family and friends the measure may have been inculcable. Future researchers may concentrate on revealing more relevant consequential factors for sexual partners and retesting the model with refined measures.

Better theories in understanding disclosure to sexual partners are needed, yet the utility of the consequences model should not be discarded. Instead, the model may need to be expanded and

further tested. It may be that matters not accounted for in this study are more predictive. For example, future researchers may include more relational variables such as power differentials, need for sex, or strength of the relationship as explanatory constructs. In addition, issues such as feeling an obligation or duty to tell may be important and more predictive for sexual partners than family or friends. Perhaps a refined consequence model would be more heuristic in understanding disclosure to sexual partners if other personal (e.g., anxiety, personality) or social (e.g., social support, perceived stigma) variables were included.

In addition to new theories and better measures, researchers may also consider taking a qualitative approach to the study of consequences and disclosure to sexual partners. Studies utilizing focus groups or individual interviews may have an advantage of tapping into a phenomenon that is so important yet remains elusive.

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Figure 1.
Theories of disclosure.

Table 1.
Means and Standard Deviations for Rewards and Cost of Disclosing

Rewards Item	<i>M</i>	<i>SD</i>	Costs Item	<i>M</i>	<i>SD</i>
1. Keep them safe from HIV	4.45	.94	1. We would fight	3.78	1.44
2. Understanding	3.99	1.12	2. Person would lecture me	3.72	1.24
3. They had a right to know	3.93	1.34	3. Person would blame me	3.53	1.44
4. I could count on the person	3.79	1.23	4. Person would be burdened	2.82	1.28
5. Get emotional support	3.39	1.37	5. Person would be concerned	2.79	1.28
6. Improve the relationship	3.36	1.30	6. Relationship would get bad	2.79	1.41
7. Be more connected	3.32	1.35	7. Might lose the relationship	2.60	1.50
8. Would bring us closer	3.31	1.45	8. Person would not want to be around me	2.59	1.51
9. Person could help me	2.69	1.51			
10. I could blow off steam	2.36	1.27			

Reward scale $M = 3.46$, $SD = .75$. Cost scale $M = 2.92$, $SD = .95$.

Table 2.Point Estimates and *t* Values for Models

Disease Model			Consequences Model			Revised Consequences Model	
Path	Point Estimate	<i>t</i> Value	Path	Point Estimate	<i>t</i> Value	Path	P
Symptoms ← Disease	0.383	2.92*	Symptoms ← Disease	0.318	4.14*	Family ← Disclosure	
Infections ← Disease	0.823	3.52*	Infections ← Disease	1.000	0.00*	Friends ← Disclosure	
Time ← Disease	0.338	2.75*	Time ← Disease	0.284	3.61*	Sex Part ← Disclosure	
Family ← Disclosure	0.814	1.11	Family ← Disclosure	0.615	3.46*	Reward ← Consequences	
Friends ← Disclosure	0.244	1.04	Friends ← Disclosure	0.313	2.59*	Cost ← Consequences	
Sex Part ← Disclosure	0.129	0.87	Sex Part ← Disclosure	0.169	1.41	Disclosure ← Consequences	
Disclosure ← Disease	0.151	0.84	Reward ← Consequences	-0.349	-4.65*		
			Cost ← Consequences	1.000	0.00*		
			Consequences ← Disease	-0.042	-0.50		
			Disclosure ← Consequences	0.473	3.21*		

* Indicates significant path.