

# PERCEPTIONS OF FAMILY BOUNDARIES

## THE CASE OF DISCLOSURE OF HIV TESTING INFORMATION

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*This study investigates the role of gender, relational status, and family role in perceptions of appropriateness of disclosure of HIV testing information. Participants included 104 dating couples and 98 married couples. Results of the factor analysis indicated participants discriminated clearly among three groups of family members. Individuals reported more desire to disclose to the marital subsystem, moderate to the nuclear subsystem, and least to the extended subsystem. Directions for future research and implications for social policy and family therapists are discussed.*

Family privacy concerns the delineation of informational boundaries for who receives what knowledge about the family. Perception of family privacy is one area of family science, communication, and therapy that has received little attention. This is surprising considering the technological advancements that have changed individuals' abilities to restrict access to information about personal and family matters. For example, gaining access to individuals' and families' financial, health, consumer, and educational records has become relatively simple (see Carroll, 1975; Ernst & Schwartz, 1977).

One specific area that has heightened concern regarding family privacy, and privacy in general, has been increased human immunodeficiency virus (HIV) testing (see Greene, Parrott, & Serovich, 1993; Serovich, Greene, & Parrott, 1992). Access to information regarding HIV testing is an important area for studying privacy issues because the release of this information has profound implications for both individuals and their families. Knowledge of an HIV-positive status can be beneficial because infected individuals can obtain prompt medical treatment and be counseled on appropriate risk-reducing behaviors in the hopes of diminishing the potential for further transmission of HIV. In addition, individuals and families can be directed to sources of social support.

Although knowledge of an HIV-positive status has some benefits, it can also result in stigma and discrimination for both persons living with acquired immunodeficiency syndrome (AIDS) and their families (Geis, Fuller, & Rush, 1986; Macklin, 1988; Rowe, Plum, & Crossman, 1988; Stulberg & Buckingham, 1988). Researchers have found that worry over this kind of disclosure results in both increased stress (Frieron, Lippman, & Johnson, 1987) and family arguments (Stulberg & Buckingham, 1988). In addition to the person

living with AIDS (PLWA), family members fear potential loss of employment, housing, and medical attention (Anderson, 1989). Furthermore, legal experts have begun to explore the increased possibility of divorces and/or annulments supported by accusations of fraud (Glen, 1990; O'Brien, 1987) as well as loss of child custody for persons testing HIV positive (Miller, 1990).

This study has two purposes. The first is to investigate whether the relational status of an individual (married or dating) is a useful way of understanding perceptions of appropriateness of disclosure of HIV information. The second purpose is to expand on research examining privacy and HIV testing (Serovich et al., 1992) to further delineate, from a systems theory perspective, perceptions of appropriate family targets for information concerning HIV testing.

### RESEARCH ON PRIVACY

Privacy, as a communication variable, has a significant impact on relationships. American society places great value on not only the right to, but the loss of, privacy (Burgoon, 1982). Just as relational development is important to humans, so is the disassociation of self from others and the ability to control others' access to self (Burgoon et al., 1989). According to Burgoon (1982), privacy is a multidimensional construct consisting of the ability to control and limit physical, interactional, psychological, and informational access to the self or one's group. This definition proposes a four-facet structure to privacy: physical, social, psychological, and informational. Although each of these dimensions is important when considering the specific case of HIV testing, this research focuses on informational privacy. This aspect of privacy is meaningful because of the potentially damaging effects of disclosure for families and individuals.

Informational privacy is related to the type of data about an individual that are released or are accessible to others (Carroll, 1975). Attitudes toward who should receive information about HIV status vary considerably, and laws are inconsistent (rights of individuals versus right of the state). For example, in most states HIV testing is anonymous and voluntary. Exceptions to these laws include, but are not limited to, persons residing in penal institutions, those implicated in sexual assault cases, or situations in which health care professionals have been exposed to blood or bodily fluids. Additionally, some states (e.g., Colorado, Delaware, and Utah) have penalties for violations of medical confidentiality laws. (For a review of state laws see Campbell, 1990; Closten et al., 1989; Hermann & Schurgin, 1991)<sup>1</sup>.

Besides regulation of who is tested for HIV, restrictions on whom physicians can notify and what information can be given also vary substantially. For example, in many states partner notification programs have been established. These programs, such as those in Iowa, Illinois, and Kansas, grant physicians who cannot successfully persuade patients to notify a spouse/partner about an HIV-positive test result the authority to notify those persons who are potentially at risk. Physicians, however, are not mandated to disclose information in these cases.

<sup>1</sup>Laws concerning these matters change rapidly. Please consult with a local attorney or state statutes concerning access to HIV testing information, confidentiality, or penalties resulting from indiscriminate disclosure.

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## Personal Relevancy

Outside of the legal arena, little is known about attitudes toward disclosure of HIV testing information. Privacy theorists might contend the issues to be examined pertain to the content of the information, degree of control over the information, and the amount of information others possess (Burgoon, 1982). This research, however, considers the crucial issue to be the extent to which the HIV status information is personally relevant to potential recipients.

In the case of HIV testing, individuals who perceive themselves as potentially at risk might want more disclosure of this information than individuals who do not perceive the information to be personally pertinent. For example, individuals who are married might not perceive others' HIV status as personally relevant because they perceive themselves to be at low risk. Individuals who are not married, however, might perceive such information as highly relevant and therefore want access to HIV testing information. Therefore, it is hypothesized:

Persons who are married will be less likely to support disclosure of HIV testing information than those who are dating.

## Boundary Formation

One way to understand the role of personal relevance within families is by using a systems approach. According to systems theory, boundaries are "the rules defining who participates, and how" which function "to protect the differentiation of the system" (Minuchin, 1975, p. 53). It is further proposed that "the composition of subsystems organized around family functions is not nearly as significant as the clarity of the subsystem boundaries" (Minuchin, 1975, p. 54). Thus, systems theory is a useful way of understanding how informational boundaries in families are created.

For individuals faced with disclosure of sensitive information, such as results of HIV testing, family boundaries might be closed and restrictive or open and unconfined. According to Walker (1991), family secrecy, or restrictive boundaries, over an HIV-positive diagnosis may be interpreted as "an attempt to protect the family from outside harm" (p. 125). Examples of potential harm could include public ridicule, harassment, or embarrassment. Walker's (1991) position, however, must be balanced against the potential harm resulting from not disclosing. Potential harm could include things such as limited

social support or inadequate medical attention.

Families attempting to negotiate boundary flexibility risk experiencing "boundary ambiguity," the uncertainty of who is a member of the family system (Boss, 1977; Boss & Greenberg, 1984). According to Boss and Greenberg (1984), in facing a stressor the amount of ambiguity a family experiences is a predictor of the amount of stress that family will experience. Families that fail to clarify boundaries cannot organize to meet the demand of the stressor and, as a result, experience elevated levels of stress (Boss & Greenberg, 1984). Boundary formation, therefore, is important for HIV testing, and a semipermeable boundary may need to be established. Such a semipermeable boundary ensures adequate input in the forms of education, medical treatment, and social support, which are provided without potential negative consequences in the forms of lost employment, housing, or education. Thus, there may be a need for both privacy and disclosure for adequate family functioning.

It has been previously demonstrated that individuals delineate clear boundaries among marital, community, and general public subsystems in perceptions of the appropriateness of disclosure of HIV testing information (Serovich et al., 1992). What occurs *within* families, however, is unclear. For example, it is not known if mothers or fathers are viewed as more appropriate recipients of HIV testing information than siblings or aunts/uncles. Case studies have reported reactions of family members ranging from acceptance to denial, from anger to disassociation (Walker, 1991).

From a systems theory position, it would seem that boundaries would develop concerning the disclosure of information according to the personal relevancy for the target person. That is, individuals would delineate boundaries by stratifying levels of the system within the family (i.e., marital, nuclear, and extended family) and make decisions about disclosing HIV testing information based on these levels. Spouses, lovers, or former spouses would be perceived as the most appropriate target for disclosure of this information because of their potential risk for infection. Nuclear family members such as mothers, fathers, sons, daughters, sisters, and brothers would be perceived as the next most appropriate subsystem for disclosure, and family members who would occupy the most private group would be the extended family, including grandparents, in-laws, aunts, uncles, and cousins.

Therefore, it is hypothesized:

Individuals will create boundaries based on desire to disclose information about results of HIV testing among the following subsystems: marital, nuclear, and extended.

## METHOD

### Participants

Participants ( $N = 404$ ) consisted of 104 couples who had been dating at least six months and 98 married couples. This sample was gathered by trained undergraduate researchers at a large southeastern university. Each participant received a survey with a set of instructions. After completing the questionnaire, which took approximately 15 minutes, the participants were debriefed and thanked for their participation. This study is part of a larger research project examining attitudes towards HIV testing.

The dating individuals ranged in age from 18 to 33 ( $M = 21.98$ ,  $SD = 2.44$ ) and had been dating, on average, for 25 months ( $R = 6$  to  $96$ ,  $SD = 19$ ). Most of these dating couples were college students. These individuals generally considered their dating relationship exclusive (94%); however, only 10% were cohabitating and 13% engaged to be married. The married individuals ranged in age from 19 to 78 ( $M = 39.68$ ,  $SD = 11.49$ ) and had been married, on average, for 16 years ( $R = 1$  to  $55$ ,  $SD = 11$  years). For 87% of these individuals this was their first marriage, and participants had between 0 and 8 children ( $M = 1.96$ ,  $SD = 1.45$ ).

### Measurement Instruments

The dependent variable, attitude toward disclosing results of HIV testing, was measured by eighteen 5-point Likert-type questions. Stimulus statements were assertions such as "Spouses should have access to information about results of AIDS tests," and statements were manipulated by changing the target of disclosure. Targets included the following: spouses, former spouses, lovers, mothers, fathers, sisters, brothers, sons, daughters, cousins, grandmothers, grandfathers, aunts, uncles, mothers-in-law, fathers-in-law, sisters-in-law and brothers-in-law. Responses to items ranged from *strongly disagree* (5) to *strongly agree* (1), with a high score reflecting greater desire for privacy and a low score indicating more interest in disclosing HIV testing information.

For the hypothesis that individuals would create boundaries concerning disclosure of HIV testing information, mari-

tal subsystem was defined by the target's spouses, former spouses, and/or lovers. The nuclear family was defined as mothers, fathers, brothers, sisters, daughters, and sons. The extended family was defined as consisting of grandmothers, grandfathers, aunts, uncles, cousins, mothers-in-law, fathers-in-law, sisters-in-law, and brothers-in-law.

## RESULTS

### Hypothesis 1

It was hypothesized that persons who were married would be less likely to desire disclosure of HIV testing information than persons who were dating, and this hypothesis was partially supported. To explore the possibility that results varied by gender, repeated measure analyses of variance were performed for all three subsystem factors by relational status (married/dating) and gender (within couple). For the marital subsystem, both the relational main effect [ $F(1, 198) = 3.96, p \leq .04$ ] and the gender main effect [ $F(1, 198) = 7.92, p \leq .01$ ] were significant. That is, males ( $M = 1.71$ ) and dating individuals ( $M = 1.70$ ) were less likely to desire disclosure of HIV testing information for the marital subsystem than females ( $M = 1.54$ ) and married individuals ( $M = 1.55$ ). There was no significant interaction between gender and marital status.

For the nuclear subsystem, there were no significant main effects for gender or relational status. That is, males and females were as likely to desire disclosure of HIV testing information to the nuclear family as dating and married individuals. An interaction between gender and relational status, however, existed [ $F(1, 198) = 3.69, p < .03$ ]. Tests of simple effects showed that although married men ( $M = 2.49$ ) desired significantly less disclosure to the nuclear subsystem than married women ( $M = 2.19$ ), the difference was not significant for dating men ( $M = 2.26$ ) and dating women ( $M = 2.34$ ; see Figure 1).

There were also no significant main effects for gender or status for the extended family subsystem. The interaction effect, however, was again significant [ $F(1, 198) = 4.86, p < .03$ ]. Tests of simple effects revealed that married males ( $M = 3.60$ ) were less likely to disclose HIV testing information to the extended family than married females ( $M = 3.35$ ), but the difference between dating males ( $M = 3.31$ ) and dating females ( $M = 3.44$ ) was not significant (see Figure 2).

Figure 1. Interaction Between Marital Status and Gender for Disclosure to the Nuclear Family



### Hypothesis 2

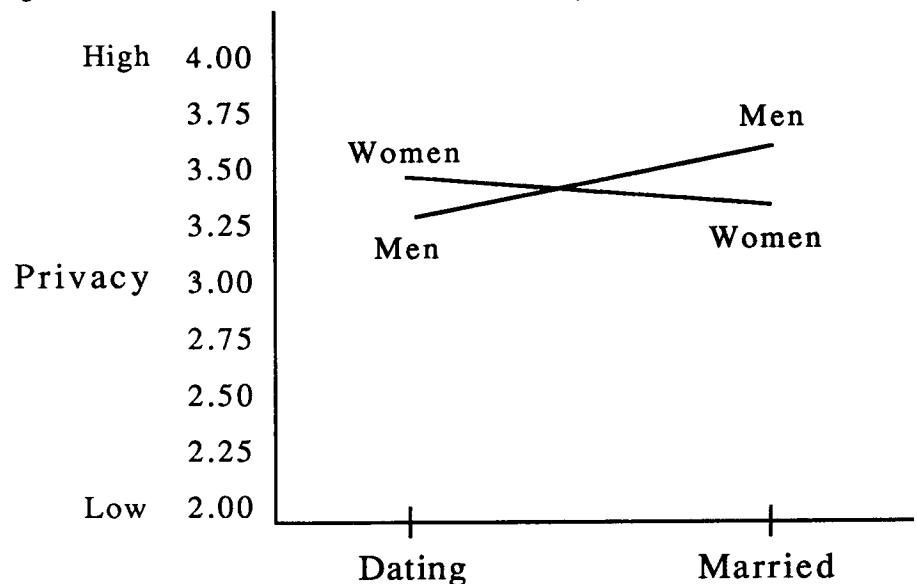
In order to test the hypothesis that individuals will create boundaries among the marital, nuclear, and extended family based on desire to disclose information about results of HIV testing, the data were analyzed using exploratory factor analysis (varimax rotation) and 95% confidence intervals. The criterion for factor retention was an eigenvalue greater than 1.0, and criteria for item retention were a primary loading of greater than .65 and no loadings greater than .35 on other factors.

Results of the initial factor analysis indicated the items *sisters*, *brothers*, *grandmothers*, and *grandfathers* loaded on both the nuclear family and extended family factors. They were, therefore,

dropped from further analyses. Factor analyses were then performed with the remaining 14 targets.

Results of the subsequent factor analysis yielded a 3-factor solution which accounted for 85% of the variance (see Table 1), which supported the hypothesis. The first factor (eigenvalue = 8.24), labeled *extended*, was comprised of the target's aunts, uncles, cousins, mothers-in-law, fathers-in-law, sisters-in-law, and brothers-in-law. These seven items were averaged to form a composite scale, and the internal consistency of this scale was excellent ( $\alpha = .98$ ). The second factor (eigenvalue = 2.36), labeled *nuclear*, was comprised of mothers, fathers, sons, and daughters. These four items were summed and averaged to form a composite scale, and

Figure 2. Interaction Between Marital Status and Gender for Disclosure to Extended Family



the internal consistency of the composite was excellent ( $\alpha = .95$ ). The third factor (eigenvalue = 1.30), labeled *marital*, was comprised of spouses, former spouses, and lovers. These three items were averaged to form a composite scale, and the internal consistency of this composite was good ( $\alpha = .75$ ). These three composite scales were used for all analyses in this study.

Further support for the hypothesis was found by examining differences in mean scores using 95% confidence intervals for each of the three composite variables. Mean scores for the three composites, marital (1.52-1.69), nuclear (2.23-2.43), and extended (3.33-3.53), were found to be significantly different. Individuals reported least desire to disclose HIV testing information to the extended ( $M = 3.43$ ;  $SD = 1.05$ ), some desire to disclose to the nuclear ( $M = 2.32$ ;  $SD = 1.05$ ), and most desire to disclose to the marital subsystem ( $M = 1.63$ ;  $SD = .73$ ).

## DISCUSSION

These data suggest informational privacy boundaries clearly exist for individuals among the marital, nuclear family, and extended family subsystems. For this study, as with previous research (Serovich et al., 1992), individuals identified the marital subsystem as the most appropriate target for disclosure of HIV testing information. This should not be surprising, considering the degree of potential risk of contraction for these individuals. This finding also supports the personal relevancy explanation of disclosure.

The appropriateness of disclosure of HIV testing information was not always clearly differentiated by the nature of the relationship in this study. Specifically, four targets (sisters, brothers, grandmothers, and grandfathers) were exceptions to the clarity of family boundaries found in this study. These may represent examples of boundary ambiguity regarding appropriate targets for disclosure of HIV testing information. Individuals may be uncertain about how comfortable they are when deciding to disclose to siblings and grandparents. What is especially interesting, and gives credence to the personal relevancy premise, is that these ambiguous targets were not differentiated by gender. Specifically, female family members were not uniformly viewed as appropriate recipients of HIV testing information. It was the role of the person (e.g., mother, sister, aunt), not simply the gender, that distinguished attitudes toward disclosure of this sensitive information.

Table 1.  
*Factor Matrix for Desire to Have Access to Results of HIV Testing Information*

Item	Extended Factor 1	Nuclear Factor 2	Marital Factor 3
Cousin	.94		
Aunt	.93		
Uncle	.93		
Sister-in-law	.92		
Brother-in-law	.91		
Father-in-law	.89		
Mother-in-law	.89		
Father		.87	
Mother		.87	
Daughter		.85	
Son		.85	
Spouse			.83
Former Spouse			.82
Lover			.73
Eigenvalue	8.24	2.36	1.30
% of Variance	58.8	16.9	9.3

Although not a primary construct under investigation, gender differences were evident for regulating privacy to the marital subsystem. That is, males were less likely to support disclosure of HIV testing information than females. This is significant considering the importance of communication regarding HIV status with partners. Interestingly, these gender differences did not hold for the other subsystems.

### Marital Subsystem

For the marital subsystem, there were differences in perceptions of appropriateness of disclosure by relational status. Those dating were less likely to disclose HIV testing information to the marital subsystem than married individuals. This is contrary to a "relevancy of information" premise which would predict that, because dating individuals are supposedly at more risk for infection, they would desire more information about HIV status. There are two plausible explanations for these results. First, what may be in operation is a form of "ignorance is bliss" factor. That is, dating persons may not want information that creates dissonance regarding their behavior. Second, dating individuals may not perceive themselves as being at greater risk than married individuals. In this case, the information may not be perceived as highly relevant by dating individuals. In fact, most of the dating couples reported their relationships to be "exclusive," and this may have affected responses. Individuals who are dating numerous people might perceive HIV testing information as highly relevant.

What were not ascertained in this study, and is important considering these findings, are factors which make communication about HIV status information relevant. In addition, are dating individuals equally private concerning

disclosure to them by a sexual partner? It is not known if the rules of disclosing highly stigmatized information are different from the rules of receiving such information.

### Nuclear Subsystem

For the nuclear subsystem, there were no significant differences by gender or relational status, but an interaction was found. Although married men desired more privacy to the nuclear subsystem than married women, dating men did not perceive privacy to the nuclear subsystem differently than dating women (see Figure 1). Married men were the least likely to want HIV testing information disclosed to the nuclear family. This suggests men may perceive privacy as more contextual, while women may regard it as more stable, but this needs to be explored further.

### Extended Subsystem

While there were no significant differences by gender or relational status for the extended subsystem, an interaction was again found. Again, married men desired more privacy than married women, but dating women and men did not have significantly different views of privacy to the extended family (see Figure 2). Married men were the least likely to want HIV testing information disclosed to the extended family. Again, perceptions of privacy may be more stable for women than for men.

## IMPLICATIONS

### Implications for Therapists

In working with HIV-positive persons and their families, therapists need to be sensitive to established informational boundaries. Decisions about disclosure to others may, in fact, be some of the most difficult decisions for HIV-positive persons and their families. Therapists need to help families affected by HIV define family boundaries, thus reducing potential conflict arising over such decision making processes (Stulberg & Buckingham, 1988). What is important therapeutically is not necessarily the targets within boundaries but the clarity of the boundary in differentiating between family members.

Results of this study should provide guidelines for therapists in helping families negotiate these boundaries. It is important to note, however, that the distinctions between subsystems found here do not reflect individual differences in family boundary formation. Therefore, therapists need to respect the deci-

sions individuals and families make in creating boundaries that reflect their own levels of comfort.

Specific decisions about disclosure of highly stigmatized information to siblings and grandparents may be especially difficult. It is plausible the ambiguity found here points to the presence of another variable, such as the nature of the relationship. There may be times when the relevancy of the information to a target is not clear. Decisions to disclose, therefore, might depend on the quality of the relationship with that sibling or grandparent. For example, disclosure to an especially close sibling would be different from disclosure to a sibling with whom a tense relationship exists. Despite what might be in operation here, decisions regarding disclosure to these family members might take additional deliberation and preparation. Therapists, aware that certain members of a family system might be more difficult to disclose to than others, can be sensitive in working with clients.

### *Implications for Social Policymakers*

Although individuals reported the marital subsystem as being the most appropriate target of disclosure, this does not mean laws need to be made to mandate such disclosure. Individuals in this study did not report authorizing disclosure, but merely viewed these targets as most appropriate to be informed. In fact, these results support efforts of policymakers to differentiate targets of disclosure. The laws that are being created to protect individuals' privacy are, according to this study, in accordance with what people view as appropriate.

It would also seem important that partner notification programs, which inform at-risk persons anonymously, continue to be developed. These programs meet the needs of persons living with AIDS, their families, and the public in two ways. First, they preserve the privacy of the person living with AIDS by not supplying identifying information to those at risk. Such nonidentification procedures, if made known to the public, might encourage individuals to be tested and voluntarily submit names of others who may be at risk. Second, partner notification programs provide a means to reach those at risk, thus affording them prompt access to medical attention, social support, and education.

What is needed is a national policy to establish programs that respect the privacy rights of those tested and anonymously locate and inform those who may be at risk. Additional information

such as name, address, gender, and age, mandated by some states, may not be advisable in balancing the needs that protect the public and encourage voluntary HIV testing. Therefore, the basis for establishment of partner notification programs needs to focus on providing anonymous testing and notification of at-risk persons.

## FUTURE RESEARCH

These results suggest that membership in a family is not perceived as an automatic guarantee of an individual's right to access to HIV testing information about another family member. Clearly, some target roles were not perceived as appropriate recipients of this information. The most important distinction in perception of appropriateness of disclosure appears to be relevancy. Future researchers might clarify how relevancy of information facilitates productive family communication regarding highly stigmatized material.

It is equally important to consider what processes individuals use when making decisions about disclosure of such material to family members. Fundamental constructs might include degree of emotional closeness, physical proximity, tolerance for differences, communication effectiveness, or relational history. Any of these variables could have an effect on disclosure and should be examined further.

Although it has been clearly documented that stigma is associated with HIV/AIDS, the possibility of stigma having a function in regulating privacy remains unexplored. For example, how an individual contracts HIV may be a significant variable in predicting patterns of disclosure. Individuals who contract HIV from a blood transfusion might be more likely to disclose their HIV-positive status than an individual who becomes infected by unsafe sexual practices. What may be in operation is a type of double stigma, or a combination of stigma resulting from both HIV status and mode of contagion. It is equally plausible, however, that because the disease carries such immense stigma, how a person becomes infected may be less relevant. These issues should be explored further.

Additionally, the findings presented here need to be replicated to see if they hold constant for populations more closely associated with the disease. These might include persons living with AIDS, those who have been tested for HIV, and family members of persons living with AIDS. These persons might perceive family informational privacy

differently from those who are not directly affected by the disease. Privacy has not been explored extensively; an investigation of other populations would be a meaningful addition to the understanding of the phenomenon. With the spread of HIV, privacy and disclosure of HIV testing information is and will continue to be a salient issue for families.

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