

## Boundaries and AIDS Testing: Privacy and the Family System\*

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*This article explores perceptions of privacy in AIDS testing from a systemic perspective. It is hypothesized that individuals will create boundaries based on desire to disclose information about results of AIDS testing. Results suggest individuals delineate clear boundaries for the dissemination of information concerning AIDS testing, with the target of information being a significant determinant of amount of disclosure. Implications for therapists, family life educators, and policymakers are discussed.*

Family life has always been profoundly influenced by crises. One such recent event that may permanently have an impact on family life has been the Acquired Immune Deficiency Syndrome (AIDS) epidemic. The disease has been identified as follows: "Acquired immunodeficiency syndrome (AIDS) is a specific group of diseases or conditions which are indicative of severe immunosuppression related to infection with the human immunodeficiency virus (HIV)" (Centers for Disease Control, 1991, p. 1). It has been estimated that for every one person with AIDS (PWA), eight family members and/or intimate others are affected (Altman, 1989). Countless other persons in the extended family, community, workplace, and school system are also affected. The incidence of AIDS may increase as much as 10 times in the next 5 years (Landers, 1986), a possibility with direct implications for family life as potentially millions of families face the loss of a member.

There is no question that AIDS has become a highly visible phenomena in the United States today. As of February 1991, the Centers for Disease Control (CDC) reports 167,803 cases of AIDS/HIV in the United States, with a national rate of 16.5 per 100,000 (CDC, 1991). With this growing incidence in the United States, countless numbers of people have been, are, and will be affected, and a number of institutions have addressed the issue with policy statements. Many school systems, colleges, and corporations have formal policies. In addition, other groups, (e.g., the American Red Cross and United States Armed Forces) have policies regarding disclosure of AIDS testing results.

This article explores perceptions of privacy in AIDS testing from a systemic perspective, offering insight to therapists, policymakers, and other community systems that are in contact with PWAs and their families. Anderson (1989) proposes that "family" should be defined as "including, in addition to the traditional biological and legal relationships, those committed relationships among individuals which ful-

fill the function of family" (p. 195). For the purpose of this article, "family" refers to immediate members such as spouses, lovers, children, parents, and siblings. Because of the sensitive nature of an AIDS diagnosis and the balance between public well-being and desire for personal and family privacy, it is crucial to establish what persons are viewed as appropriate recipients of AIDS testing information.

Systems theory describes how information is shared between families and their environment by focusing on the structure or boundary which separates systems. Minuchin (1975) defines the boundary of a family system as "the rules defining who participate, and how" (p. 53). The function of this boundary "is to protect the differentiation of the system" (p. 53). In addition, for healthy family functioning, the boundary that delineates the family must be clear and well defined, yet flexible.

The flexibility of a family boundary is particularly important during a crisis because it can serve to protect and give identity to a system. Ironically, for families including a PWA, the desire for privacy in closing family boundaries conflicts with needs to be flexible and allow external/outside input in the form of health care, therapy, and information. Cleveland, Walters, Skeen, and Robinson (1988) found that 47% of parents of homosexuals would not want anyone outside of the family to know of the AIDS diagnosis, and 16% would not even want the diagnosis shared with other family members. These findings are especially disconcerting given that this population came primarily from support groups of parents of lesbians and gays, and only 53% of these parents of gay men and lesbians reported that they would respond to an AIDS diagnosis by expanding boundaries and disclosing information.

The loss of any family member is substantial and its effect is multidimensional. When that member is a person with AIDS, the needs of the family (including intimate others) are extensive. These include counseling, support, understand-

ing (Geis, Fuller, & Rush, 1986), and a reorganization of one's life (Tiblier, Walker, & Rolland, 1989). Often overlooked needs are for religious affiliation, spiritual life, and direction (Greif & Poremski, 1988; Warner-Robbins & Christiana, 1989). The availability of information on the disease process, transmission, and nutrition has also been noted as important for PWAs and their families (Greif & Poremski, 1988).

Families are also confronted with a wide variety of emotions when a member is diagnosed with AIDS. They experience helplessness, (Frierson, Lippman, & Johnson, 1987; Greif & Poremski, 1987), grief (Stulberg & Buckingham, 1988; Tiblier et al., 1989), guilt over not having protected the child (Stulberg & Buckingham, 1988), blaming of one parent by the other (Rowe, Plum, & Crossman, 1988), and isolation (Geis et al., 1986; Macklin, 1988). What these families experience is further complicated by fear of infection and contagion (Frierson et al., 1987; Macklin, 1988). Lovers and spouses specifically fear further sexual contact with the PWA (Frierson et al., 1987; Tiblier et al., 1989), pressure to leave the relationship (Tiblier et al., 1989), powerlessness (Greif & Poremski, 1987), and anger (Macklin, 1988, 1989; Stulberg & Buckingham, 1988). Homosexual PWAs have the added fear of increased victimization or "gay bashing" (Larsen, Long, & Serra, 1987).

One of the most profound effects on families and intimate others is the stigma

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and discrimination resulting from an AIDS diagnosis (Geis et al., 1986; Macklin, 1988, 1989; Rowe et al., 1988; Stulberg & Buckingham, 1988). Worry over potential disclosure of the AIDS diagnosis significantly increases stress for both PWAs and their families (Frierson et al., 1987). Arguments over disclosing to friends and extended family, as opposed to keeping it an immediate family secret, are common (Stulberg & Buckingham, 1988). Fear of potential consequences of such disclosure is understandable for PWAs and their families. Patients fear abandonment or rejection by co-workers, neighbors, and/or friends (Stulberg & Buckingham, 1988) as well as the loss of their employment, right to an education, housing, and other services, including medical attention (Anderson, 1989).

Some predict that the workplace may become the "most prevalent arena for AIDS related discrimination in the near future" (Anderson, 1989, p. 202) as employers fire and/or make testing mandatory in the workplace. It is also predicted that, in the 1990s, privacy in the workplace may be the most substantial social issue (Hoerr, 1988). For example, PWAs are suing employers over breaches of confidentiality when co-workers learn of the diagnosis (Bullock & Faber, 1989). In addition, while reports of PWAs losing their jobs are common, in some instances family members have been fired or forced out of employment (Frierson et al., 1987).

Discrimination due to an AIDS diagnosis has also been identified in other areas (Frierson et al., 1987). Highly publicized cases have shown children with AIDS being denied admission to the classroom. The effects of discrimination have also reached the home front with landlords attempting to evict PWAs (Anderson, 1989). While in most states this action is illegal, the discrimination may take more subtle forms such as refusing to make residential repairs or substantially increasing rent (Anderson, 1989). An AIDS diagnosis has, therefore, indirectly forced people to live on the streets or in shelters.

The AIDS epidemic has also affected individuals attempting to acquire health or life insurance. Some companies now require a negative HIV test to obtain coverage and have terminated coverage for persons with AIDS, along with refusing to cover treatment costs (Anderson, 1989). Numerous others in helping professions (e.g., therapists and physicians) and civil service positions (e.g., ambulance drivers) have refused to assist AIDS patients. If funeral homes service PWAs, they frequently increase their rates (Greif & Porembski, 1988) and/or refuse to

embalm or otherwise service the body. Therefore, the issue of privacy in AIDS testing is a vital one for PWAs and their families.

Privacy is a multidimensional construct, as highlighted by Burgoon's (1982) definition of privacy as "the ability to control and limit physical, interactional, psychological and informational access to self or one's group" (p. 210). The perceived appropriateness of privacy, or freedom from disclosure of information, is particularly affected by the potential recipient of the information. Privacy has been studied as a construct in several settings (for review see, Burgoon, 1982). Greene, Parrott, and Serovich (1991) examined perceptions of privacy and AIDS testing and found privacy needs to be the strongest indicator of individuals' views about disclosure of results of AIDS tests and knowledge of who has been tested for AIDS.

This research extends the investigation of Greene et al. (1991) to encompass issues about the saliency of privacy and AIDS testing in families and identify appropriate targets for such disclosure:

*Hypothesis 1:* Individuals will create a boundary between family and community based on desire to disclose information about results of AIDS tests.

*Hypothesis 2:* Individuals will create a boundary between family and community based on desire to disclose information about who has been tested for AIDS.

*Hypothesis 3:* Individuals are more likely to want to keep AIDS diagnoses secret from people outside the family than from family members.

## Method

### Participants

Responses ( $N = 327$ ) were gathered from people in the southeast. The sample for this study consisted of college students ( $n = 151$ ) and unassociated parents ( $n = 176$ ). This sample is part of a larger omnibus project examining privacy in AIDS testing (see Greene et al., 1991). Participants ranged in age from 18 to 70 ( $\bar{X} = 30.3$  years), with the sample being 61% female ( $n = 201$ ) and 39% male ( $n = 126$ ). Students were contacted through undergraduate communication classes at a large southeastern university. Parents were part of a convenience sample collected by trained undergraduate student researchers. These students and parents received a survey with a set of instructions. After completing the questionnaire, which took approximately 10 minutes, students and parents were debriefed and thanked for their participation.

## Instruments

Two variables of interest in this study, desire to restrict access to both results and knowledge of who has been tested, were measured by 5-point Likert-type scales. Responses ranged from *Strongly Disagree* to *Strongly Agree*. Both instruments were composite, averaged indices with a high score indicating greater privacy wants and a low score indicating more interest in allowing access to this information.

*Desire to restrict access* to results of AIDS tests was measured with a composite score comprised of 11 questions. Stimulus statements were assertions such as "Employers should have access to information about results of employees' AIDS tests." The statements were manipulated by changing the target, and the targets were presented as follows: employers, potential employers, newspaper, general public, co-workers, community leaders, teachers, classmates, spouses, family members, and lovers. The reliability of this scale was good ( $\alpha = .85$ ).

*Desire to restrict knowledge of who has been tested* was measured by nine 5-point Likert-type items with duplicate target areas (same as access to results). One question reads, "Employers should have access to information that employees have had AIDS tests." The only target items which were not duplicated were newspaper and general public. The reliability of this scale was also good ( $\alpha = .86$ ).

Hypotheses for this study proposed a distinction between recipients of AIDS testing information from family and community areas. *Family* in this study was comprised of the items indicating family members, spouses, and lovers. *Community* was comprised of the items indicating employers, potential employers, newspaper, general public, co-workers, community leaders, teachers, and classmates.

Two additional 5-point Likert items measured desire to keep AIDS testing information secret. The first item asked participants to respond to "If I had AIDS, I would want to keep it a secret from other family members." The second item stated "If I had AIDS, I would want to keep it a secret from persons outside the family." Responses on these items ranged from 1 to 5, with a lower score reflecting more desire for secrecy.

## Results

The data were analyzed by exploratory factor analyses (varimax rotation) and confidence intervals. Criteria for factor retention were eigenvalues greater than 1.0 for retained factors, and criteria



for item retention was a loading of greater than .65 and factor loadings of .35 or less on all other factors. For both factor analyses, the "family" item split loaded between community and family. The item "family," therefore, was dropped from further analysis. The factor was retained and renamed "marital subsystem" and includes spouses and lovers. The item "classmates" was also dropped from *desire to have access to results* due to ambiguous factor loadings. Therefore, confirmatory factor analyses and reliabilities were rerun including only items that met the criteria.

It was hypothesized that individuals would create a boundary between family and community based on desire to disclose information about *results of AIDS tests*, and Hypothesis 1 was supported based on the distinction between the marital subsystem and community. However the analysis showed that the proposed community grouping split into two factors. Therefore, results of the factor analysis for *desire to have access to results* yielded a three-factor solution which accounted for 73% of the variance. The first factor (eigenvalue = 3.54), "community," was comprised of the items: employers, potential employers, co-workers, and teachers (alpha = .85). The second factor (eigenvalue = 1.70), defined as "general public," was comprised of the items: newspapers, general public, and community leaders (alpha = .84). The third factor (eigenvalue = 1.32), "marital subsystem," was comprised of the items: lovers and spouses (alpha = .61).

Further support for Hypothesis 1 was found by examining the difference in mean scores by calculating 95% confidence intervals for each variable. For *desire to restrict access to results*, all three factors (marital subsystem, community, and general public) were significantly different. That is, individuals reported more desire to restrict access to results of AIDS tests to the general public ( $\bar{X} = 4.14$ ), moderate to community ( $\bar{X} = 3.27$ ), and minimal or no desire to restrict access for the marital subsystem ( $\bar{X} = 1.66$ ).

It was also hypothesized that individuals would create a boundary between family and community based on desire to disclose information about *who has been tested* for AIDS, and Hypothesis 2 was supported based on the distinction between marital subsystem and community in desire to restrict knowledge of who has been tested for AIDS. Results of the factor analysis for *desire to have knowledge of who has been tested* yielded a two-factor solution which accounted for 67% of the variance. The first factor (eigenvalue = 3.92), "community," was

comprised of the items: employers, potential employers, co-workers, community leaders, teachers, and classmates (alpha = .87). The second factor (eigenvalue = 1.41), "marital subsystem," was comprised of the items lovers and spouses (alpha = .77).

Further support for Hypothesis 2 was found by examining the difference in mean scores by calculating 95% confidence intervals for each variable. For *desire to restrict knowledge of who has been tested*, the two factors (marital subsystem and community) were also significantly different. That is, these students and parents reported a desire to restrict knowledge of who has been tested to general public ( $\bar{X} = 3.72$ ) and moderate desire to allow knowledge for marital subsystem ( $\bar{X} = 1.95$ ).

When examining differences between *access to results* and *knowledge of who has been tested* by factors, scores for marital subsystem were significantly different. Individuals reported more desire to restrict knowledge of who has been tested ( $\bar{X} = 1.95$ ) than access to results of tests ( $\bar{X} = 1.66$ ).

The final hypothesis proposed that individuals would be more likely to want to keep AIDS diagnoses secret from people outside the family than from family members, and this was supported. In order to test Hypothesis 3, 95% confidence intervals were calculated for desire to keep secret from the family and desire to keep secret from persons outside the family. While these items were significantly correlated ( $r = .337, p < .001$ ), the mean scores for the secrecy items were also significantly different. Participants (parents and students) were more likely to want to release information about AIDS to family members ( $\bar{X} = 3.7$ ) than to persons outside the family ( $\bar{X} = 2.3$ ).

## Discussion

The results of this study suggest that individuals delineate clear boundaries for the dissemination of information concerning AIDS testing. The target or recipient was a significant determinant of whether information about AIDS testing should be released. In general, people were more interested in having access to results of AIDS tests than knowledge of who has been tested across all factors.

"Family" as a hypothesized factor did not hold under analysis; it split between "marital subsystem" and "community." There are two plausible explanations for this finding. First, the term "family" encompasses a wide range of persons. These students and parents may have responded in terms of the nuclear family (e.g., parents or siblings) or the extended family (e.g., aunts, uncles, or grandpar-

ents). In this instance, the wording of the question may be suspect. A second explanation rests on what Boss (1977) refers to as "boundary ambiguity" or uncertainty as to who is in the family system. Individuals may be unclear as to which family members they feel comfortable disclosing information about AIDS testing.

As predicted, disclosure to intimate others was seen as the most appropriate target for release of information about both results of AIDS tests and knowledge of who has been tested. In addition, individuals are more interested in keeping the secret from people outside the family than from family members. The results of this study suggest that, in response to the desire for privacy in AIDS testing, people react in ways to tighten or restrict family system boundaries. These restrictions on information are in direct conflict with needs of PWAs and their families for information, counseling, and support.

Not predicted, but nonetheless important and encouraging, is the distinction between community and general public for desire to restrict access to results of AIDS testing. It was not seen as appropriate to publish results in the newspaper or to make them available to the general public or community leaders. However, individuals were moderately willing to release information about results of AIDS tests to the community, and this may suggest that people understand the importance of community support. As individuals become increasingly educated about AIDS, and discrimination against PWAs diminishes, they may be willing to reach out to employers, co-workers and teachers for valuable support during such crises.

The distinction between community and general public did not appear for knowledge of who has been tested. The only difference for knowledge of who has been tested was the distinction between community and the marital subsystem. This finding is understandable given that just because someone has been tested for AIDS does not qualify that person as a threat to public health or individual well-being since they may not be HIV-positive. In general, knowledge of who has been tested for AIDS was not seen as relevant information when compared to results of AIDS tests.

## Implications for Therapists

PWAs are likely to receive diagnoses from physicians in hospital or clinic settings, and it is in these settings where initial efforts are made to connect individuals with counseling and other support services. Reception of this diagnosis can produce a number of personal crises



and issues, one of which is privacy or disclosure issues and dilemmas. Therapists, social workers, and counselors in hospitals and clinics need to be aware of privacy needs and assist PWAs with negotiation of boundaries by discussing implications and appropriateness of who to tell and how. With knowledge of the hierarchy of boundaries described in this article (marital subsystem, community, and general public), counselors can assist in these negotiation efforts, perhaps one boundary or level at a time. This may entail dealing initially with intimate others and family, and later co-workers, friends, or classmates. Therapists may see PWAs (and/or intimate others) who do not want to disclose to their family, potentially hindering the therapeutic process. PWAs cannot receive needed support from family and friends if they completely close boundaries and refuse to disclose.

Counseling provides an important opportunity for individuals to receive comfort and support for negotiating the dissemination of information to certain audiences while suggesting how to control the information with regard to other targets. Galanes and Berquist (1991) report several behaviors that counselors of families with a seriously ill family member did not find to be supporting, and these include reminders of loss of friends; possible loss of life; and the loss of privacy, an issue of particular salience for this research.

Therapists, aware that privacy issues exist, can help PWAs and their families acknowledge and negotiate these boundaries as well. It must be understood that the disclosure process is not limited to the PWA but affects the entire family (Macklin, 1988). Decisions about who to tell creates stress and arguments for families (Stulberg & Buckingham, 1988) and may be one of the initial conflicts the family faces. Families may disagree as to the level of disclosure that feels safe or comfortable, such as if the PWA decides to go public (i.e., general public level) with the diagnosis. Because of the unpredictable nature of the disease process (see Friedland, 1990), the family may need to adjust to some level of disclosure rather quickly.

One of the primary reasons individuals desire privacy concerning their AIDS diagnosis is due to the possibility of resultant stigma and discrimination. In fact, Greene et al. (1991) found that privacy needs, attitudes toward homosexuality, and religiosity were the best predictors of attitudes toward disclosure of AIDS testing information, reinforcing the social implications of the AIDS testing controversy. Results of this study suggest that counselors may need to spend consider-

able time with clients and their families dealing with potential stigma and discrimination issues.

Family members of PWAs may also seek out, either individually or together, therapy or support to deal with the crisis. Families may need these services long after the diagnosis and impending death, and Anderson (1989) notes that AIDS has the potential to negatively impact the family system. Family members may continue to feel anger, helplessness, and extreme loss long after the death occurs. In addition, some members may feel relief that the ordeal is over, with grief perhaps confounded by guilt. These members will require therapy to handle these issues and possible subsequent discrimination they directly face, which in some communities may not easily dissipate.

Services and support groups that ensure anonymity exist in most communities, and these agencies should be actively reaching out to community members who may be locked in closed boundaries, ceasing input into the system, or are overwhelmed with caretaking tasks. Publicity of services of therapists and support services must be highly visible, and it is imperative that community groups network to provide and make available the widest range of services.

### **Implications for Family Life Educators**

These findings indicate clear levels or targets for disclosure of information regarding AIDS, and it will be important for family life educators to be aware of these levels and what may affect choices to disclose in each of the target groups (marital, community, and general public). Fear of stigma and discrimination may be primary factors in these decisions to disclose to the three groups. Accurate information regarding etiology and contagion of the AIDS virus is important for discouraging risky behavior. Equally important, however, is a need to teach this information in a climate of tolerance. If stigma and discrimination are primary factors in decisions of PWAs and their families to not reach out for help, then explaining facts and dispelling myths around risky behavior will be important.

Family life educators can facilitate the reduction of this discrimination in three ways, all related to privacy. First, educators can promote open classroom discussions about homosexuality, bisexuality, prostitution, drug abuse, and other potentially high risk-related groups and behavior. The aim of such discussions would be to help students develop a healthy tolerance, if not acceptance, for lifestyle differences, again addressing the finding of Greene et al. (1991), which

suggests that social attitudes (religiosity and acceptance of homosexuality) were significant predictors of attitudes toward AIDS testing. Hepworth and Shernoff (1989) suggest that AIDS education should emphasize risky behaviors which cause infection rather than membership in high-risk groups. The distinction between group membership and behavior is important, but reduction of homophobia and other forms of discrimination, through dispelling myths, may be indirectly helpful for some families to open boundaries regarding AIDS testing information.

Secondly, such discussions might be combined with guest speakers who are, or have family members who are, members of high-risk groups or HIV-positive. This would allow students the opportunity to question firsthand individuals they might not otherwise meet. Dispelling myths about the supposed "risky groups" will be important because research has shown sharp reduction in the incidence of AIDS in the gay community (Winkelstein et al., 1987) but marked increases in previously "low-risk" adolescent, minority, and women's populations (CDC, 1991). While the groups which are stereotypically perceived as being at risk may have changed, societal perceptions may not have. Thirdly, it is important for family life educators to be aware of and teach information regarding local and state AIDS testing policies and privacy laws.

### **Implications for Social Policy**

Macklin (1988, 1989) suggested that PWAs and their families fear contagion, social stigma, infection, abandonment, as well as experience guilt, anger, and economic hardship. These fears and feelings exist for family members and PWAs, potentially producing limited disclosure. The resulting stigma and discrimination of an AIDS diagnosis affects each family member in the potential loss of employment, co-worker and classmate harassment, and so forth. It is therefore, important that public policies be written to protect these privacy rights.

Numerous policies do currently exist to address the issues surrounding AIDS and AIDS testing. Some school systems, in Georgia for example, require both students and employees to report HIV infection, with confidentiality ensured. Institutions of higher education have also addressed the issue with many following the recommendations published by the American College Health Association which state, for example, that students infected with the AIDS virus may participate in campus activities. While many organizations have developed policies to deal with the presence of PWAs, policies and laws have been developed to restrict



access to information regarding AIDS testing (e.g., California, Georgia), identify specific targets for which disclosure is legal and appropriate (e.g., Idaho), protect PWAs who are involved in AIDS-related research (e.g., Florida, Illinois, Maine), and provide specific penalties or violations for disclosure of this information (e.g., California, Georgia) (Hermann & Schurgin, 1991). Some states, however, such as Arizona, Colorado, Kentucky, Minnesota, South Carolina, and Wisconsin, require the reporting of subjects' names along with positive HIV antibody tests (Hermann & Schurgin, 1991).

What will be necessary in the future, for social policy, will be standardization of policies (governmental, professional, and community) regarding AIDS, and Anderson (1989) notes that AIDS policies should be designed to strengthen and foster support for PWAs and their families. Because of the possible negative consequences of an AIDS diagnosis, policies must account for potential threats to the family as well as the individual (Anderson, 1989). Moving toward national policies regarding employment, educational, and housing discrimination for PWAs and their families would be a step in this direction, but national policies protecting the right to privacy will be necessary as well, as evidenced by these findings.

Because there is limited evidence of potential danger to others through casual contact, those who test should define what happens to the results. While numerous institutions have developed policies regarding AIDS testing, these policies will be modified in the future. For legislators and administrators contemplating these reforms, this information about societal attitudes will be extremely salient, as will the clear desire of respondents to restrict access to information about persons tested for AIDS.

Some laws and policies now in effect may discourage disclosure of information, thereby doing a disservice to families who struggle to deal with social, financial, and emotional losses. (For a comprehensive review of state laws, see Campbell, 1990; Hermann & Schurgin, 1991.) People responded in the present study that the only relevant "group" for dissemination of this information was the "marital subsystem" and felt that they should have the right to privacy as it does not affect the well-being of others. Intimate others (marital subsystem) was seen as most appropriate for release, and clearly these are the individuals who may be at risk of infection. Risk to other groups is minimal, and this study shows that overall, people do not want information released to community nor general public subsystems.

More research needs to be done to help the general public understand the transmission of the disease so that a PWA is not seen as such a threat to others' individual health. While more education on transmission is needed, this alone will not change attitudes toward perceived risk groups and PWAs, and this points to the necessity for protection of these groups.

### Limitations

One limitation of this study is that the investigation format asks people to imagine their responses or anticipate their reactions to AIDS. While this study shows that a large proportion had no contact with PWAs (73% reported not knowing anyone who had tested HIV-positive nor anyone who had died from AIDS), when confronted with the actual situation, responses might be more extreme, possibly reflecting an even more closed boundary. Conversely, if individuals were to be faced with a family member with AIDS, the negotiation between levels of community systems might be clearer. That is, they might have more of an investment for effective communication across boundaries.

Alternatively, the sample for the present study consists of parents and college students, and these individuals may be widely separated from their families. While the effect of distance from family on attitudes toward privacy and disclosure would be interesting to investigate, the students and parents in this study were unassociated. Responses from families with young adults living at home, compared with those living away from home, could be markedly different. Perhaps future research could include distance as an additional predictor, in addition to sampling family systems instead of cross-sectional age/family stage cohorts.

### Future Research

There are several issues which need to be addressed in future research. First, it is plausible that "family" as a hypothesized factor did not hold as a factor due to boundary ambiguity. This result is especially disconcerting considering the potential role of extended family as a valuable support during crises. Individuals with a family member with AIDS may find disclosure to those outside the family easier than inside the family because of the fears and stigmas associated with the disease. Because the disease signifies unacceptable behaviors, immediate family members may prefer to hide the diagnosis or cause of death in an effort to bar disgrace. Some PWAs or family members may choose never to disclose and cover up or misrepresent the cause of death, however, due to the terminal nature of the

AIDS disease at present, eventually most family members are likely to discover the diagnosis. Therefore, future research needs to focus on what factors may comprise acceptable or appropriate family recipients of this information. What is also unclear is the function extended family members might play in dealing with this crisis.

The respondents for this study consisted of college students and unassociated parents. Future research regarding privacy in AIDS testing may focus on other populations, and some could include PWAs and their families, health care workers, and other high-risk groups such as homosexual and bisexual men and prison populations. In addition, it is important to examine if these boundaries related to AIDS testing are constant for other disease processes such as STDs, cancer, and Alzheimer's. The stigma associated with any of these diseases may also affect privacy and family functioning.

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