HELPING HIV-POSITIVE PERSONS TO NEGOTIATE THE DISCLOSURE PROCESS TO PARTNERS, FAMILY MEMBERS, AND FRIENDS

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For people who have been diagnosed with a chronic illness, one inevitable issue to be addressed is whether and how to share this information with others. For persons who are HIV positive, disclosure presents an especially arduous task. The purpose of this article is to offer a strategy to assist marriage and family therapists in facilitating client disclosure of an HIV-positive status to partners, family members, and friends. In addition, suggestions for setting the stage for disclosure to occur and recommendations for client follow-up are proposed.

INTRODUCTION

For people who are diagnosed with a chronic illness, one issue inevitably to be addressed is whether to share this information with others. Researchers have documented that some people disclose information when they feel distressed and obtain some benefit by doing so (Derlega, Metts, Petronio, & Margulis, 1993; Greenberg & Stone, 1992; Pennebaker & Beall, 1986). For instance, those who disclose freely visit physicians less frequently, demonstrate unimpaired immune function, and exhibit autonomic nervous system regularities to greater degrees than their nondisclosing counterparts (Pennebaker, Colder, & Sharp, 1990). Researchers have also demonstrated that suppressing thoughts or communication about burdensome experiences can increase the likelihood of stress-related difficulties (Greenberg & Stone, 1992). Given these findings, the relationship between disclosure and mental health is important for both therapists and researchers to explore.

Although disclosure when one is distressed has potential benefits, persons with a chronic illness may be in a difficult situation when the information is stigmatizing or potentially damaging. This is especially true for HIV-positive persons because sharing their diagnosis can provoke anxiety and perceived threats to personal well-being. As Bolund (1990) stated in regard to cancer, “There is only one disease, AIDS, that has a similarly strong attribution of dread” (p. 13). For HIV-positive persons, anxiety or stress may center around fears of impending physical deterioration or lack of quality and availability of medical treatment. In addition to physical stressors, broad social stressors are associated with and HIV/AIDS diagnosis, such as fear expressed by others, ostracism, and degradation, as well as stressors within the individual’s family network, such as denial, anger, guilt, and uncertainty (Frierson, Lippman, & Johnson, 1987; Herek & Glunt, 1988; Macklin, 1988). Emotional consequences of disclosure including rejection, abandonment, and isolation have been extensively documented (Lovejoy, 1990; Stulberg & Buckingham, 1988; Zuckerman & Gordon, 1988). These negative consequences are exacerbated if disclosure also leads to an admission of particular sexual or drug-using behaviors. Similarly, physical, social, and emotional stressors associated with the disclosure of an HIV-positive diagnosis can be confounded by fear of or actual loss of employment, insurance, housing, medical services, child custody, or right to an education (Anderson, 1989; Herek &...

With these anticipated repercussions, telling family members of one’s HIV-positive status is likely to be tenuous, difficult, and tension filled (Kimberly, Serovich, & Greene, 1995; Walker, 1991). In studies of HIV disclosure to family members, friends, and community associates, rates of disclosure varied from family member to family member and were typically lower than rates of disclosure to sexual partners (Hays et al., 1993; Mansergh, Marks, & Simoni, 1995; Marks et al., 1992; Mason, et al., 1995). The family members most likely to learn of an HIV-positive diagnosis were mothers (Mason et al., 1995) and sisters, while fathers were the least likely (Hays et al., 1993; Marks et al., 1992). Typically friends were more likely to receive HIV information over all possible family members (Hays et al., 1993; Mansergh et al., 1995; Marks et al., 1992a; Mason et al., 1995).

Disclosure to significant sexual or drug-sharing others appears to be different than to family and friends. Rates of reported disclosure to sexual partners vary and, in some studies, have been remarkably low. For example, although Hays et al. (1993) reported that 98% of their sample disclosed to lovers/partners, other studies have reported disclosure rates to sexual partners of 89% (Schnell et al., 1992), 76.3% (Marks, Richardson, Ruiz, & Maldonado, 1992b), 66% (Perry, Ryan, Fogel, Fishman, & Jacobsberg, 1990), 65% (Marks et al., 1992a), and 48% (Marks, Richardson, & Maldonado, 1991). Researchers have attempted to explain these variations by reporting correlates with demographic variables such as ethnicity (Mason et al., 1995), degree of symptomatology (Mansergh et al., 1995), level of relationship commitment (Perry et al., 1994), or number of sexual partners (Marks et al., 1992a). For example, the likelihood of disclosure decreased in direct proportion to the number of partners (Marks et al., 1991). Similarly, Perry et al. (1994) reported that individuals were less likely to inform casual partners of their HIV status than steady partners. From this research, individuals with HIV appear to be selective about disclosing their serostatus and tend to inform significant others more frequently than nonsignificant others (Greene & Serovich, 1996; Marks et al., 1992a).

The purpose of this article is to offer a strategy to assist marriage and family therapists (MFTs) who work with HIV-positive clients to help them disclose their status to partners, family members, and friends. This strategy has been informed by research (Greene & Serovich, 1996; Hays et al., 1993; Mansergh et al., 1995; Marks et al., 1992a; Mason et al., 1995; Perry et al., 1994; Serovich & Greene, 1993; Serovich, Greene & Parrott, 1992), numerous research interviews (see Kimberly, et al., 1995; Serovich, Kimberly, & Greene, 1998), and clinical work with HIV-positive individuals.

**STEPS TOWARD DISCLOSURE OF AN HIV-POSITIVE DIAGNOSIS**

This section presents a detailed description of one strategy for assisting HIV-positive persons in disclosing their serostatus. A few caveats should be noted. First, individuals should be selective in deciding whom to tell. Clearly, an HIV diagnosis should not be uniformly revealed to everyone in a social network. Advocating disclosure without careful consideration of each individual person and potential consequences is unprincipled and can be harmful. Second, although many HIV-positive persons choose to disclose to their close social network members at once so as to “get it over with,” others prefer not to. Typically those diagnosed with HIV have time to consider potential consequences, weigh them carefully, and make thoughtful decisions concerning disclosure. Encouraging clients to wait and complete the proposed exercises, however, is not appropriate if disclosure has not occurred with a sexual- or intravenous drug–using partner with whom risk behaviors are occurring. In these cases, clients should be counseled about the responsibility to disclose, or at the very least, to use safer sexual and needle-sharing strategies.

Third, the strategy presented here is designed to help persons who may be undecided regarding whom or how to tell. It should be used as a guiding procedure and not a rigid template. This approach can be employed with individuals who have recently been diagnosed as well as those who have known their serostatus for years. In addition, although this approach was developed from the direct experience of persons who are HIV positive (or have AIDS), it could be applied to anyone who shares the burden of disclosing this information to others. Therefore, mothers, fathers, sisters, brothers, or friends of HIV-
positive individuals might benefit from considering the following issues and exercises. Further, although these exercises are written primarily for MFTs, these activities and ideas could be utilized by a range of helping professionals such as doctors, nurses, support-group leaders, volunteer "buddies," and others who work with persons struggling with disclosure. It should be noted that the steps or exercises are described in a sequential order and while it is preferable that these steps or exercises follow this progression, adding, skipping or deleting steps along the way might be beneficial for some.

Before beginning, therapists should always assess the physical and emotional well-being of their clients to ensure that any serious medical or emotional needs are met immediately. As with other crisis situations, the most significant needs should be addressed first. For HIV-positive clients, issues to be assessed include the level of depression that might block the person from following through on tasks, as well as signs of disease progression that might interfere with exercise completion. In addition, professionals should assess the size of the social network, level of satisfaction with sources of support, current relationship status, and type or extent of unmet medical or physical needs. Because disclosing an HIV-positive diagnosis can be difficult and emotionally laden, professionals should be knowledgeable about existing and potential support structures, including support groups, community organizations, partners, friends, and family to whom the client already has disclosed or with whom he or she has an association. These supports may be drawn upon to assist the client as he or she proceeds in the disclosure process.

**Step 1: Making a Disclosure List**

The first step is to encourage the client to take an inventory of all persons to be considered for disclosure. Developing a thorough list of possible recipients serves a number of purposes. First, this process allows the individual and therapist to assess the size and composition of the client's social network. Even if disclosure does not occur to many or most individuals on the list, these people may be available to provide other assistance. Second, assessing the social network can be a validating experience for clients who have an adequate network by offering the opportunity to reflect on the depth or breadth of preexisting support. Even clients with few identified persons in their social network can feel empowered if these relationships are of high quality. In fact, during research interviews in which social support networks were assessed, it was not unusual to hear participants comment on how the exercise enlightened them to the extent of their available social network. Therapists should, however, be prepared for situations in which clients have very few social contacts and express distress at this revelation. Such situations present opportune times to introduce clients to formal support groups.

The list should include persons who are important to them, those with whom they interact regularly, those with whom they socialize, and those they consider to be family, friends, acquaintances, associates, or even enemies or adversaries. It is important to make this list exhaustive, including those persons who already know of the HIV-positive status of the client, those who would not understand if told (e.g., very young children), those the client believes they would never tell (e.g., elderly grandparent, grocer, clergy, or neighbor), those to whom they are unsure about telling (e.g., boss, coworker, or parents), and those whom they want to tell most (e.g., children, partners, or spouses).

This exercise is meant to ensure a thorough list; therefore, therapists might assist clients in identifying possible recipients with questions such as "with whom do you work?" or "where do you shop, dine, play, or visit?" The construction of a family genogram (see McGoldrick, Gerson, & Shellenberger, 1999) might offer the most comprehensive view of biological or extended family members to be considered. Furthermore, it may be helpful for clients to carry a pad and pencil for a week or two and write down the names of persons with whom they regularly interact. This exercise might be especially useful for those reporting limited social networks.

During the list-making stage, an HIV-positive person should be encouraged to refrain from making a firm decision not to disclose to any one particular person. It is helpful if everyone is initially considered as a possible recipient of disclosure to avoid prematurely eliminating any one. With the steps and exercises described here, concrete reasons for nondisclosure may present themselves. By allowing such reasons to be fully explored, ambivalence, hesitancies, or feelings about disclosing can be more adequately addressed.
Step 2: Evaluating the Nature of Each Relationship

Next, MFTs should encourage individuals to evaluate the nature of the relationship and the level of satisfaction with each person. This step is important because although the initial reaction of the recipient might be that of shock, surprise, or even anger, researchers have found disclosure of an HIV-positive condition typically does not damage strong, intact relationships (Kimberly et al., 1995). In fact, in many instances HIV-positive persons report that relationships deepen or are brought to a more intimate level after disclosure. At the same time, a poor relationship is rarely strengthened and may be worsened by such news. Having this information, therapists can assist clients to prepare appropriately for potential reactions.

Researchers have found that individuals evaluate the consequences and rewards of disclosure before deciding to tell (Marks et al., 1992a). Typically these are idiosyncratic to the relationship between the recipient of the information and the person disclosing it. Therefore, clients should be encouraged to evaluate the nature of their relationship with each potential recipient. A Likert-type scale might serve to rate the relationship in terms of satisfaction: 1 = very dissatisfied, 2 = dissatisfied, 3 = neither dissatisfied or satisfied, 4 = satisfied, 5 = very satisfied. Whether or not such a scale is used, respecting client context is important, and the best strategy is for the therapist and client to develop a relevant means of assessing the strength of each particular relationship. For example, "strong" or "intimate" may be more fitting for some relationships than "satisfied."

Using this type of scaling technique, individuals can better decide if the relationship quality is substantial enough for disclosure to occur. Again, the decision is purely subjective but a score of 4 or 5 might indicate that the relationship is strong or important enough for disclosure to occur. If this is the case, the client may choose to proceed in the decision-making process. If, however, the relationship quality is rated as a 1 or 2, clients have two options. The first is deciding not to disclose at this time. If individuals choose this option then they should decide if or when they will deal with the problematic relationship issues. However, even though the relationship quality may be poor, disclosure may still be desired for reasons such as obligation or a desire to avoid perpetuating secrets. In this instance, the client may proceed in the decision-making process.

Step 3: Assessing a Recipient’s Special Circumstances

The next step is to assess other special circumstances that might preclude disclosure, such as the recipient’s mental stability, physical health, age, or personal crises. The location of the recipient (e.g., jail) may, for some, be a deterrent. Additionally, a client may refrain from telling a person if he or she fears they may tell others without consent. Special circumstances affecting the decision to disclose may include whether or not the potential recipient’s condition is chronic or one that will dissipate quickly. In some cases disclosure can wait while the recipient recovers from a short-term illness or crisis situation. Other circumstances may persist or worsen and may be obstacles to disclosure. These distinctions are important as clients might choose to make different decisions about disclosure based on the nature of the special circumstances.

In the case of HIV disclosure, one particularly important circumstance for many is the age of the recipient. Age may also influence who should do the disclosing and how it should occur. For example, it may be more appropriate for very young children to be told by a parent with or without the HIV-positive person present. In addition, the actual content disclosed, or the level of explicitness about the illness may depend on the child’s age. For example, young children may be given modified information (“Aunt Joan is very sick” instead of “Aunt Joan has kaposi sarcoma associated with the HIV virus”) and updated in a developmentally appropriate manner. Each particular case should be discussed, as children of a similar age may have differences in developmental maturity.

Individuals commonly question whether or not to tell the elderly of an HIV-positive diagnosis. Typically, these are grandparents, aunts, or uncles; however, for some, these may be older parents or older siblings. Commonly expressed fears include whether they will understand the nature of HIV, or if the news will be too shocking for a frail elder and will result in worsened health. Little research has been conducted on disclosure of HIV status to the elderly but anecdotal evidence from research interviews and work with clients suggests that the elderly are no more or less affected by HIV disclosure than others. In fact, one young man revealed during therapy that his elderly family members handled his disclosure better than most...
of his family. His explanation for their reaction was that given their age they had “seen it all” and were not surprised by bad news.

When a potential recipient’s circumstances are an issue, two options are available: (1) that person can be placed in a “wait and see” category, as in the case of a transient psychological or physical illness, or (2) that person might be placed in a “not to be told” category, as may be the case in extreme illness. If persons are placed in the “wait and see” category it may be fruitful to continue to evaluate disclosure. If they are placed in the “not to be told” category, reassessment should occur in the future.

Step 4: Assessing HIV Knowledge and Anticipated Reactions

Individuals who are knowledgeable about HIV or who know someone with HIV may be more accepting; therefore, it may be helpful for clients to consider others’ level of HIV knowledge or attitude. First, do potential recipients know others who have been infected? If so, how did they react? What does that relationship look like now? How has the person reacted to news broadcasts or medical updates about HIV/AIDS? If it is unclear whether they know other HIV-positive persons, then how have they reacted to other bad news or difficult information? In addition, how opinionated are they about issues related to sexual orientation, sex, drugs, race, gender, and ethnicity? Does the client think the potential recipient suspects the diagnosis? Researchers have found that reactions to an HIV disclosure are less intense if family members already suspect the individual is HIV positive because they have had time to adjust even without direct knowledge (Seroевич, et al., 1998).

HIV-positive persons may be frightened by the expected reactions of others. In research interviews, anticipated reactions perceived as poor or rejecting were the primary reasons for not disclosing (Kimberly, et al., 1995). Statements like “They would disown me if I told them” were common. If the client has little information about a potential recipients’ knowledge or likely reactions, others who know them can be asked to assess their possible reaction. Such a step can serve to either validate their concerns or cast aside unfounded fears. If consultation with others is not possible, clients might be prompted to recall if they have witnessed the persons exhibiting past prejudicial or discriminatory behaviors. The crucial issue is that if the potential recipient has little background or knowledge of HIV, the client may have to educate them. This could entail offering educational material or information about support resources available to partners, family, or friends. Using those to whom one has already disclosed as a “barometer” for reactions can also be beneficial in garnering support. In addition, therapists may suggest clients “test the waters” with those anticipated to be the most supportive. This is beneficial because studies have suggested that telling others becomes easier with experience and practice (Kimberly, et al., 1995).

When HIV knowledge and anticipated reactions of potential recipients are not an issue, the client can proceed in the decision-making process. In the event that they are a significant issue, the options described above are available.

Step 5: Why Disclose?

The final step is to assess the reasons why disclosure to potential recipients is important. Researchers have indicated that reasons for disclosure are varied and include receiving instrumental and expressive support and feeling a sense of obligation to warn others (Kimberly, et al., 1995). Instrumental support can take the form of help with child care, running errands, or acquiring accurate disease information. Expressive support could include needing to vent feelings, being supported, or feeling loved. For some, disclosure results from a sense of obligation—a desire to warn or help another person, or a need to protect them from infection. It is helpful for individuals to identify why they are disclosing so they can request needed assistance or meet desired goals.

Step 6: Making a Decision

After information about each person in the social network has been assessed, each person can then be placed into one of three categories: (1) to be told now, (2) to be told later, and (3) wait and see. Those placed in the “to be told later” list should include individuals who are deemed appropriate for future disclosure but are not presently appropriate recipients due to special circumstances. These persons may be young, or may
be experiencing physical, emotional, or other transient crises. Persons placed in the “to be told later” category might also include individuals with whom the HIV-positive individual has a poor or problematic relationship. Clients might wait to tell these persons until the situation is improved. Those placed in the wait and see” list should include individuals with an uncertain illness duration, a poor or absent relationship, or strong biases against HIV-positive persons. These persons might not be told now, but remain on the social network list for possible future disclosures. Finally, those placed in the “to be told now” list might be included in the next series of exercises.

DISCLOSING AN HIV-POSITIVE STATUS

Once a decision to disclose has been made, the following suggestions may be helpful. First, individuals should be encouraged to pick the time and place for disclosure carefully as these factors can make a difference in response. Disclosure is not advisable late in the evening or when recipients are tired, experiencing stress, or emotionally unavailable. Disclosure is also not advisable in hurried, crowded, noisy, or distracting situations. Helpful questions for clients considering disclosure include, “If you have a choice of where to tell this person, where would you both feel most comfortable? When would be a good time of day?” Not surprisingly, many situations are not conducive to disclosing, such as being outside in a public place, in a bar or crowded restaurant, or under the influence of alcohol or drugs. A relaxed atmosphere with minimal distractions is optimal. For example, one might choose to tell a partner after going out to lunch or taking a walk together.

Next, clients should decide how much information they will share about activities that led up to the infection. In one study, Kimberly et al. (1995) found that family members typically reacted to HIV disclosure with questions such as, “how did you become infected?” “how long have you been infected?” and “do you have HIV or AIDS?” Therefore, clients should be prepared for such inquires. Clearly, this information, although it may be requested, does not have to be part of the disclosure. A simple, “I prefer not to discuss that right now,” or “I’m not comfortable discussing that at this point” should suffice. Whether or not more information is shared is the choice of the person disclosing it, but this should be decided beforehand to help ease his or her anxiety. Clients should be encouraged to practice the disclosure. Therapists can assist by introducing role-play scenarios. Enactments can be an especially helpful exercise in a support-group setting. Rehearsals can also be performed with therapists, supportive friends, other family members, or alone.

AFTER DISCLOSURE

It is important to underscore the fact that disclosure is not an event but an unfolding process. This process should include follow up conversations to answer questions, assess any delayed reactions, or to normalize the relationship and clarify concerns that may have been unexpressed at the time of initial disclosure. For example, clients might be encouraged to reconnect with the friend or family member shortly after disclosure to ask “what concerns do you have?” “how are you feeling about all this?” or “how can I help you cope?” 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. Double disclosures are more likely to need extra follow-up attention.

Frequently, individuals continue to negotiate their interpersonal relationships by working with MFTs during the difficult adjustment periods. For example, family members often have difficulty handling this information. Therefore, it is not uncommon for HIV-positive persons to find themselves taking care of the emotional needs of others. It is important that therapists and helping professionals continue to be available to answer questions, provide support and guidance as these difficult circumstances are negotiated. If HIV-positive individuals cannot assume the burden of taking care of the family member after disclosure, arranging for someone close to the recipient (i.e., friend or other family member) to be available may be advised.

Regardless of the reaction, clients should not allow the issue of HIV infection to dissipate and not be
revisited with the recipient. One sometimes complicated situation that arises is the need of family members to talk about the disclosure with others. In this event, ground rules or limits on such discussions should be discussed and decided upon. If family members need to talk with someone, clients should be prepared to give them permission, though, for the sake of privacy some limits may be placed on who these support people might be. Therapists and helping professionals should also encourage clients to be patient with the process. For some family members and friends, the disclosure is a shock requiring time for adjustment.

CONCLUSIONS

Disclosure of an HIV-positive diagnosis can be difficult and anxiety provoking. Individuals fear negative reactions in the form of rejection, shunning, abandonment, or fear. However, because disclosure is often important for the acquisition of supportive services, it almost becomes inevitable. The steps and exercises presented here were designed to assist HIV-positive persons to make clear choices around disclosure so that it can be a positive experience.

REFERENCES


Patterns of notification by infected gay men. *Hospital and Community Psychiatry, 41*, 549–551.