FOCUS A GUIDE TO AIDS RESEARCH

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Families in Crisis: Coping with AIDS

Colleen McMillan, MSW

Families are complex social systems that are constantly in a state of flux and evolution. The process of family interactions can be a volatile one triggered by stress, anxiety or conflict. As a system, the family adapts to these changes by creating a set of coping techniques that permit its members to deal successfully with most problems. A family plagued by a series of unresolved or concurrent crises, however, can become overwhelmed with emotional stress and may regress to ineffective behavior patterns as members struggle to achieve some semblance of stability.

Such is the case for many families of people with AIDS; the person with AIDS becomes the focus of difficulty in the family system. Three areas of difficulty were found in working with the families of these patients: disclosure of homosexuality and AIDS, role differentiation, and emotional distance. This report will briefly address these common issues found among the families of origin of 30 gay men with AIDS referred for assessment and counseling to the inpatient social worker at Mount Sinai Hospital in Toronto. Common interventions for the problems raised will also be discussed. Where case examples have been used, names have been changed to maintain confidentiality.

Disclosing Homosexuality and an AIDS Diagnosis

A son's disclosure of his homosexuality is for many families the beginning of a series of crises. One father admitted his 15-year-old son to a psychiatric hospital and demanded electric shock treatment to normalize the boy. Another sent his 16-year-old son to Montreal with a one-way ticket. Disclosure usually results in a gay man's leaving his family's home and relocating to a metropolitan city where he adopts a way of life neither understood nor accepted by his family.

When a gay man must disclose his homosexuality as well as an AIDS diagnosis to his family, the impact is even more profound. And for those men with AIDS who left home in their youth after disclosing their homosexuality, old issues of resentment and misunderstanding, in addition to the AIDS diagnosis, must be addressed.

Of the 30 people with AIDS discussed here, 13 left their biological families between the ages of 14 and 17. At the time of admission to the hospital and referral to the inpatient social worker, disclosure to the family became a significant issue. Twenty of the 30 people with AIDS had not disclosed their homosexuality to their families and 21 of the 30 had not revealed their AIDS diagnoses.

Client Profile of Disclosure

Tim is a 31-year-old Roman Catholic Italian who lives with his elderly parents. They have encouraged Tim to "make us proud by marrying a nice girl and giving us grandchildren." Tim and his siblings were reared to respect the family and parents; such values are cherished as an integral part of their belief systems. Tim leads a double life, one hidden from his family and characterized by frequent sexual contact, an active night life and drug use. He tells his family that his late nights and absence of relationships with women are related to his erratic work hours. Tim has warned friends never to phone his house for fear of arousing suspicion.

In March 1987, Tim was diagnosed with AIDS and was hospitalized. He told his friends that to visit him in the hospital would prompt his family to question the relationship of these strangers to their son. While protecting his family, Tim cut off a source of support during the time he needed it most.

> *For a person with AIDS, hospitalization often represents the last opportunity for the patient and family to resolve "unfinished business" and for family members to be close and supportive.*

This case typifies a common problem involving disclosure. Two interventions have been useful in such cases: circular questioning and positive connotation. In circular questioning, questions are framed so they challenge basic assumptions about an individual's beliefs and the interactions in his family. Circular questions require members of the family to come to their own realizations about the question and to hear other family members' concerns and perspectives about the issue.

One example of a circular questioning sequence might involve asking: "Who in the family has been most supportive of Tim? Who agrees that father has been the most supportive of Tim in the past? Who in the family would be most supportive of Tim now?"

The therapist uses the answer to one question to develop the next question and allows family members to uncover their own solutions. Although the therapist may have a hypothesis about the issue being discussed, family members are allowed to develop their own understandings of the issue.

Circular questioning is a family therapy technique, but it can be useful as well in individual therapy. In terms of disclosure, circular questioning might be used in the following way. The therapist first asks the patient to identify a family member with whom he has enjoyed a positive relationship and who he feels would be the most accepting of his diagnosis. Almost all of the 30 men in this clinical series identified a female sibling. The process of identification continues until the patient has ranked all family members according to their hypothesized ability to accept

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and support the diagnosis. After disclosure is made to the first identified family member, the second most supportive individual is then involved and so on, until the diagnosis is shared with all members of the biological family.

Another helpful technique with this type of family system is positive connotation, an intervention that allows the therapist to redefine, in neutral rather than negative terms, the motivations for behavior. For example, in the case of a person with AIDS who has separated geographically from his family, a therapist might say, "It is good that there is so much distance between you and your family because if they knew how sick you were, they might be concerned, so concerned that they might want to see you."

The behavior that is positively connoted should be based on the information that the patient provides. In this case, the patient may feel that his family has rejected him in the past and he may fear rejection again. The positive connotation allows the therapist both to support the patient's behavior and to question the patient's motivations. This is done in such a way that the patient is less likely to become defensive.

The patient can also use positive connotation techniques to disclose his homosexuality to family members. For example, the therapist may encourage the patient to make a statement such as, "Because the following information is so important to me, I want to share it with you," or "Because you mean a lot to me as a parent, I want to share some information with you." In either example, emphasis is on the positive. By "sharing" feelings, rather than "reporting" them, an individual acts as peer rather than a teacher or a messenger.

Disclosure of this kind of information to the family is not always deemed the best course of action. In another case, a patient with Kaposi's sarcoma decided that disclosure of his homosexuality and AIDS diagnosis would be emotionally devastating to his elderly parents and thereby to himself. Instead, he wrote a letter to his parents expressing many of the feelings he was unable to share with them since he had left home 15 years earlier. "Because of my fear of disappointing you further as a son, I was afraid to phone in case you didn't care," he wrote. This letter was hand delivered by his lover after the patient's death. His parents expressed a great sense of gratitude and relief at not having to deal with his dying and death.

These examples illustrate the ways disclosure might be handled. In those cases where an individual wants to disclose, it is useful to have the patient envision the different scenarios that may occur upon disclosure. This allows him to identify appropriate disclosure strategies by acting out, through role playing, methods of handling reactions by family members. It is also helpful for caregivers to map out the degree of disclosure to family members and significant others through the use of a chart, which is then included with the patient's medical records.

Role Differentiation

Differentiation of self is a cornerstone in Murray Bowen's Family System Theory (see reference 1). Self differentiation reflects the extent to which a person is able to discriminate intellectual from emotional functioning. The behavior of a person who exhibits a low degree of differentiation is emotionally driven, while the behavior of someone with a higher degree of differentiation is more intellectually driven. Among the 30 individuals discussed here, many demonstrated a lower degree of self differentiation.

A correlation between a patient's low self differentiation and poor role differentiation among the members of his family was also noted. Role differentiation reflects the extent to which family members adhere to socially-prescribed roles such as mother, father, son and daughter. Thus, the lower the self differentiation of family members, the greater the difficulty each member has in fulfilling his or her prescribed role. In these situations, family members are unable to distinguish their feelings from those of other family members and adopt easily whatever emotions dominate the family.

For example, in a family where the roles of the mother and daughter are poorly defined, the mother might have difficulty disciplining her daughter because the two share the same thoughts and feelings and act as peers rather than as parent and child. This sharing of emotions may explain the need of a person with AIDS to protect his family from the disclosure; since his emotions will mirror theirs, the potential trauma of disclosure to his family may carry an equally large emotional cost for him.

Family members who have a low level of differentiation may also experience the greatest difficulty in responding to a crisis in a constructive manner. When roles in the family are confused, for instance when a mother looks to her son as a partner as well as a child, family members are left without clear and appropriate responses to crises such as an AIDS diagnosis. A case example will clarify these issues.

As a child, Michael was often forced to take sides in his parents' arguments. When his father left the family, Michael was assigned by his mother the role of "the man of the house." He was 13 at the time. In this conflicting role, Michael regularly acted as his mother's confidante, advisor and comforter. He grew up resenting these responsibilities, his mother and his younger brother. Later as an adult, when Michael was dying of AIDS, his mother vacillated between mourning for the loss of her son and of her mate. This created role conflict and emotional confusion for Michael who, aside from dealing with his own impending death, felt compelled to comfort and care for his mother.

In these types of cases, clarifying roles and boundaries within the family system allowed for more functional behavior and affective expression. This was achieved by encouraging members to establish personal identities separate from their families and by freeing them from fear of rejection or disappointment from other family members.

Emotional Distance

Upon reaching adulthood, an individual may try to resolve a problem in differentiation by distancing himself from his family, through either a geographical or a psychological separation. Murray Bowen refers to this flight from unresolved emotional issues as "emotional cutoff."

Of the 30 men in this series, 17 were not in contact with their biological families for as many as 18 years. Where contact was initiated or maintained, it was due most often to efforts of either the mother, a sister or both. In almost all cases, individuals physically moved away from the family to free themselves from unresolved issues within the family system. In fact, this strategy never resolved these issues; it simply distanced them.

While geographical separation may reduce anxiety, it also limits potential sources of support. For a person with AIDS, hospitalization often represents the last opportunity for the patient and family to resolve this "unfinished business" and for family members to be close and supportive. Times of stress, such as hospitalization and diagnosis, may also aggravate unresolved issues among family members.

There are times when emotional cutoff may be an appropriate treatment strategy. In one case, a patient hypothesized that his parents would not be supportive upon the disclosure of his diagnosis. This proved true when they did visit him. Their response paralleled and reinforced their previous rejections of him and so contact with his parents only made his situation worse.

Conclusion

The lack of existing literature about the families of people with AIDS provides the practitioner with little theoretical basis by which to deliver appropriate services. Bowen's Family System Theory applies to many of these families; however, his interventions are most pertinent to a traditional family configuration where all family members are in contact, which is rarely the case for this

client group. Similarly, the Milan technique (see reference 1) of circular questioning was originally designed and intended for use with a traditional family.

In both cases, the model can be altered to fit the unique characteristics of the family of a person with AIDS. Treatment approaches for these families will vary and must be guided by creativity, sensitivity and a respect for the singular nature of each family system and its individual members.

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References

1. Goldenberg I, Goldenberg H. *Family Therapy: An Overview.* Monterey, CA: Brooks/Cole Publishing Company, 1985.
2. Tomm, K. One perspective on the Milan Systemic Approach. *Journal of Marital and Family Therapy,* July 1984.

Diagnosis/Treatment/Prevention

AIDS and Cross-Cultural Counseling

Sally Jue, LCSW

American society is made up of many cultures. Some are based on race and ethnicity, and others, such as the gay and lesbian community, are based more on shared social behaviors. This cultural diversity is clearly reflected in America's AIDS and ARC cases. Therefore, it is essential for mental health professionals to be able to appreciate different values in order to provide effective services to those who are HIV-infected.

Culture can be defined as those attitudes, values and beliefs that influence self-perception, self-expression and perceptions of others. Often counselors and their clients are unaware of how their respective cultures influence their interpretations of each other's behaviors and the outcome of counseling. To avoid cultural misunderstandings, it is helpful to explore these issues with the client. At times, a cultural consultant may be an important resource.

Counselors must determine the level and degree of AIDS information possessed by clients. Most AIDS information is presented in English and geared towards white, middle class Americans. Since such information is often inappropriate for other cultures, it is important to assess what, if any, AIDS information is available in clients' communities, whether that information is presented intelligibly and in a culturally-appropriate manner, and how it is received and interpreted by clients and others to whom they may show it.

Many people of color and members of immigrant groups still view AIDS as a white, gay, American disease and believe that by remaining within their communities and by avoiding acculturation, AIDS can be avoided. Lack of information on how AIDS has affected a particular community or the existence of a small number of AIDS cases in a particular group reinforces denial about AIDS as a current or potential problem.

Criteria for Determining Cultural Differences

Since AIDS remains a stigmatized disease, it is helpful to examine a cultural group's history in the United States, especially if there is a history of oppression, in to order understand an individual's response to AIDS. How does the group respond to stigma and oppression? How has oppression shaped the group's response to outsiders and mainstream institutions? People from oppressed groups may have difficulty trusting outsiders and institutions, and it may be that an individual's resistance to self-disclosure or to seeking assistance is the result of the group's social history rather than individual paranoia or avoidance.

It is also important for the therapist to understand high-risk behaviors and beliefs about homosexuality, substance abuse, and multiple sex partners from the client's cultural perspective. These beliefs and how they are discussed influence clients' self-perception, self-esteem, willingness to disclose an AIDS diagnosis and involvement in potentially high-risk behaviors, and the degree to which clients feel they deserve assistance from family, friends and service providers.

Since AIDS is a life-threatening illness, it is essential for the therapist to be aware of cultural beliefs about disease, death and dying, and medical treatment. Not all clients are comfortable with Western medicine and may prefer traditional healing methods. Exploration of these issues often leads to a discussion of spiritual beliefs, which may play a key role in how a client copes with AIDS and handles decisions about suicide and artificial life support.

Social and emotional support is essential to the well-being of people who are HIV-infected, but this support may manifest itself differently from culture to culture. Examining a culture's social and familial roles, and whether or not the needs of the individual take precedence over the needs of the group, will indicate what type of support is available, and how, when, and from where it can be attained. For example, some cultures view counseling as a supportive way to lessen the burden on friends and family. Others perceive scheduling an appointment to discuss highly personal matters with a stranger as bizarre or senseless behavior.

> *Since AIDS remains a stigmatized disease, it is helpful to examine a cultural group's history of oppression, in order to understand an individual's response to AIDS.*

To enhance further communication with a client, a counselor needs to develop an understanding of how people from other cultures express themselves verbally and non-verbally. Americans tend to emphasize direct confrontation of their problems through open discussion. People from other cultures may view this as rude, intrusive, hostile or disrespectful; they may prefer a more indirect approach. In addition, they may have different expectations about non-verbal communication, such as eye-contact and body language. For example, is touching appropriate and, if so, in what manner and context?

Finally, a counselor needs to evaluate a client's level of acculturation: how well integrated into mainstream society is an individual? On an objective level, this assessment could include an appraisal of the client's command of English and ability to function at a school or job outside his or her community. On a subjective level, it might mean determining a client's comfort about being outside his or her community, about being different, and about identifying more with one particular culture.

Efforts to Make Clients Comfortable with Therapy

Clients may be in the vulnerable position of seeking help and it becomes the counselor's responsibility to make an effort to get to know the client within the client's culture. This often means developing a more personal relationship with the client in order to establish trust and alleviate anxiety about the therapist's willingness and ability to transcend cultural differences. Opening this more personal relationship may require discussion of the counselor's family, sexual preference or motives for doing AIDS work. It may also require the practitioner to accept small gifts, spend more time with home visits or share a meal with clients and their families.

Open discussion of cultural differences can be beneficial to both the client and the therapist. The client, with the therapist's assistance, will have the opportunity to distinguish between what is cultural and what is personal. If the counselor validates what

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is sexually or ethnically different, the process can alleviate the client's confusion and eliminate internalized negative stereotypes. For the practitioner, this strategy offers an opportunity to broaden skill, knowledge and experience, and to gain the satisfaction of recognizing diversity and using it to benefit the therapeutic process.

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BRIEFS

Recent Reports

Reversion to Seronegative Status. Evidence from the Multicenter AIDS Cohort Study (MACS) suggests that a small number of those who test positive for HIV antibodies will later test negative.

The authors of the study, published in the *Annals of Internal Medicine* (June 1988), state, "The possible existence of a small proportion of persons whose HIV-1 infection is undetectable by available serologic technology adds further, however minor, uncertainty to the control of HIV-1 infection."

One thousand of 3317 gay men from three sites of the study tested positive for the HIV-1 antibody, using ELISA and Western Blot testing. Of these, four men, who were asymptomatic, reverted to seronegativity during a 2.5 year period, despite the fact that polymerase chain reaction (PCR) (gene amplification) showed the presence of HIV DNA, indicating AIDS infection.

The authors offer several explanations for the loss of seropositivity including: false positive reactions; specimen mislabeling; low-level antibody contamination of a negative specimen by a highly-positive specimen; or, in what the authors call clear speculation, immunization with defective or noninfectious HIV-1. The authors dismiss some of these conditions as unlikely, however, and state that the fact that the four men were actually infected is supported by the presence of viral DNA demonstrated by PCR.

Finally, they state that, "This loss of antibody may be a newly recognized phenomenon of retrovirus infection in some persons that has no scientifically-supported explanation." Long-term follow-up is required to determine whether the men will remain seronegative.

Potential HIV Inhibitor Synthesized. Scientists have successfully synthesized parts of CD4, the protein found on the surface of human T-cells and macrophages, to which HIV initially binds after it enters the body. The discovery offers the potential for the development of a powerful HIV inhibitor.

Binding is the first step in viral infection of a cell. In the human body, the first step in HIV infection is the binding of HIV to cells that have the CD4 receptor. Researchers from the National Institutes of Health, the Food and Drug Administration and Genelabs Inc. (Redwood City, CA) reported in *Science* (August 5, 1988) that *in vitro* (in the laboratory) the addition of synthesized CD4 inhibited HIV binding to the CD4 receptors of the body's cells.

If synthetic CD4 has the same effect in human subjects, it could halt or slow HIV infection.

[Editor's note: Phase one trial testing of synthetic CD4 as an antiviral drug began at San Francisco General Hospital and New England Deaconess Hospital in Boston in mid-August. Each site is testing 15 subjects for a period of 79 days. The trial will test five dosage levels and compile data on the side effects of the drug and preliminary data on its efficacy. The trial is sponsored by Genentech, a San Francisco Bay Area biotechnology firm.]

New AIDS Virus and Variants. A new variant of HIV has been identified by a researcher in Antwerp, Belgium. The discovery was announced at a National Institutes of Health (NIH) conference on "Genetic Variation of Immunodeficiency Viruses," according to *Science* (August 5, 1988).

This virus was isolated from the cells of both partners in a married couple from Cameroon in west Africa. It is unclear, however, if it is a significant cause of disease. The husband has developed ARC symptoms such as swollen lymph nodes and chronic diarrhea but his pregnant wife remains asymptomatic.

Antibody studies of the new virus indicate that it is different from HIV-1 and HIV-2. An Antwerp biotechnology firm, working with the Institute of Tropical Medicine, is determining the nucleotide (compounds that make up DNA and RNA) sequence of the new virus' DNA. So far, a partial sequence, which differs significantly from the DNA sequences of HIV-1 and HIV-2, has been established.

Full details about the sequencing work cannot be disclosed because the firm plans to patent the new virus, which could prove valuable in the development of diagnostic techniques or a vaccine.

Also at the NIH conference, the Pasteur Institute in Paris presented research about a new variant of HIV-1, which researchers describe as a less virulent, or possibly harmless, form of the virus. An avirulent form of HIV-1 would help researchers identify the precise molecular features of the virus that cause AIDS.

Next Month

While education is recognized as a crucial strategy for controlling the transmission of HIV, very little is known about the most effective ways of communicating about AIDS. In the October issue of **FOCUS, Mark Hochhauser, PhD** will review educational techniques that can be used to present information about HIV and will discuss how to judge the readability and efficacy of written materials. Hochhauser was Director of Health Education at the University of Minnesota student health service and is now a consultant on AIDS issues.

In addition, Thomas M. Irish, PhD, a psychologist in private practice and an Adjunct Research Psychologist at the Pacific School of Psychology, and **Nancy Gourash Bliwise, PhD,** Associate Professor of Research Training at the Pacific School of Psychology, will discuss the outcomes of AIDS education on mental health professionals. They will present the results of a survey of therapists, taken before and after a training conducted by the AIDS Health Project, and will discuss how the workshop affected attitudes on such issues as homosexuality, fear of contagion, drug use, racism, and the stress involved in patient care.

FOCUS A GUIDE TO AIDS RESEARCH

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